



PATIENT CARE  
RESEARCH  
EDUCATION  
COMMUNITY

# Functionality of Electronic PROs in Clinical Care

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*Panel Presentation #3: Clinician and Patient Use of PRO Data Through EHRs*

PCORI PRO Infrastructure Workshop 11/19/2013



*A Comprehensive Cancer Center Designated  
by the National Cancer Institute*

<http://lombardi.georgetown.edu>  
Lombardi CancerLine: 202.444.4000

# The Benefits of Electronic PROs

## Easy!

- Reduction of patient burden
- PRO reports created to highlight clinical relevance

## Fast!

- Less work for staff (e.g., no data entry)

## Integrated!

- Systems
- Automated responses
- Other uses

# Do Current Systems Measure Up?



- Little is known about the range of designs and features available.
- Published papers do not focus on the systems.
- Developers have a variety of backgrounds and perspectives.

# A Review of Electronic PRO systems in Cancer Clinical Care

- 33 eligible systems identified
- Developers were contacted and completed a questionnaire about their PRO systems:
  - System Features
  - System Automation
  - PRO Reports
- 27 responded (81% response rate)

# Results

- Most systems (63%) were intended to track PROs during cancer treatment.
- Some systems (40%) were also capable of transitioning to long-term follow-up care.

## To Learn More:

Jensen RE, Snyder CF, Abernethy AP, Basch E, Potosky AL, Roberts AC, Loeffler DR, Reeve BB. A Review of Electronic Patient-Reported Outcomes Systems used in Cancer Clinical Care. *Journal of Oncology Practice*. 2013. [In Press]

# EHR Integration

- Identified by 44% (12) of systems
- Increasingly common:
  - 5+ years ago (35%)
  - 1-4 years ago (43%)
  - <1 year (100%)

# Is Electronic PRO Collection Easy?

## Page Design

51% One question per page

34% Auto advance

38% Progress bar present

## Data Capture

62% Allow multiple log-ins

76% Allow missing data

34% Allow N/A response

The screenshot shows an iPad interface for a PRO collection. At the top, the status bar indicates 'iPad', signal strength, '6:16 AM', and '69%' battery. The app header features a silver seal with '1789' and two orange buttons labeled 'Menu' and 'Help'. The main content area has a light gray background with a question: 'In the past 7 days.... My sleep was refreshing'. Below the question is a list of five response options, each with a checkbox: 'Not at all', 'A little bit' (which is checked), 'Somewhat', 'Quite a bit', and 'Very much'. At the bottom, there is a 'Prev' button, a green progress bar showing '83% completed/ 2 minutes to finish', and a 'Next' button. A small copyright notice 'Copyright © 2012 Tonic Solutions LLC' is visible at the very bottom.

# Report Content

93% Current Scores  
93% Longitudinal  
77% Interpretation  
52% Reference Values  
52% Meaningful Change  
33% Guidelines Included

Comments [View All](#)

Is there one problem in particular you'd like your doctor or nurse to address during your next visit?

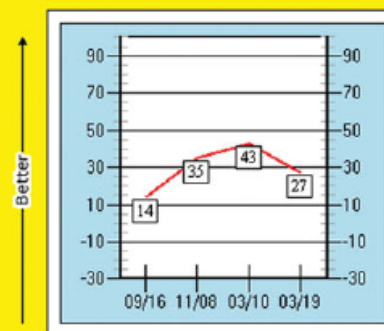
I am having trouble doing the things I need to do.

Enter any other comments or questions for your doctor or nurse.

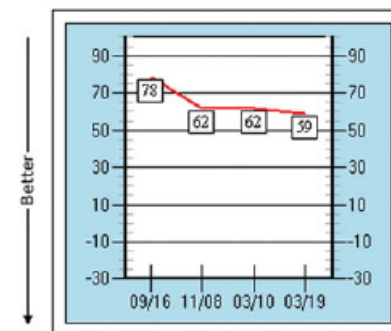
It's helpful answering these questions.

The results for the most recent and four previous surveys are graphed below. Graphs highlighted in yellow represent either a significant worsening or a score that is likely to be a problem. For a summary of the items in each score, click [What is this?](#) For an explanation of the scoring, click [Score meaning](#). For suggestions for how to address potential problems, click [What can I do?](#)

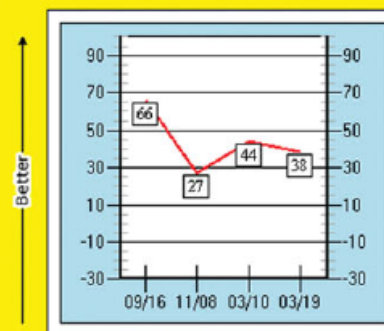
**Physical Function** - [Score meaning](#)  
[What is this?](#) [What can I do?](#)



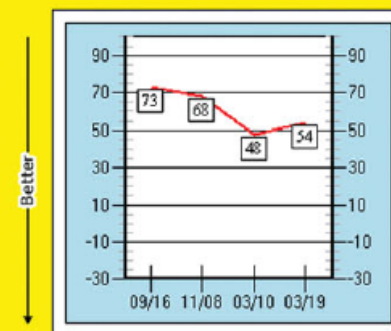
**Pain Impact** - [Score meaning](#)  
[What is this?](#) [What can I do?](#)



**Social Roles** - [Score meaning](#)  
[What is this?](#) [What can I do?](#)



**Fatigue** - [Score meaning](#)  
[What is this?](#) [What can I do?](#)





# Is Electronic PRO Collection Fast?

- **Clinic Workflow**

Assessment Location	Overall	EHR	Non-EHR
Clinic Only	30% (9)	25%	40%
Home Only	33% (8)	17%	40%
Both Options Provided	37% (10)	58%	20%

- **Staff Time**

Reminder to Patient	Overall	EHR	Non-EHR
Automatic	52% (14)	67%	40%
Manual (Letter, Phone)	15% (4)	8%	20%
No Reminder	33% (9)	25%	40%

# Is Electronic PRO Collection Integrated?

- Score-Linked Actions

Feature	Overall	EHR	Non-EHR
Alerts to Clinicians	85% (23)	100%	73%
Referrals	26% (7)	33%	20%
Patient Education	48% (13)	58%	40%

A screenshot of a digital patient assessment interface. At the top, a progress bar shows '17% completed'. The main text asks: 'Using the scale below, please indicate the number that best describes how much your distress has negatively impacted your life during the past week, including today.' Below this is a scale from 0 to 10. The scale is color-coded: 0-4 are green, 5 is yellow, 6-8 are orange, and 9-10 are red. Above the scale, there are two small bar charts: a green one on the left labeled 'No Impact On My Life' and a red one on the right labeled 'Extreme Impact On My Life'. A yellow dot is positioned above the number 5. Navigation arrows are on the left and right sides of the scale.

# Is Electronic PRO Collection Integrated?

- Other Linked Systems

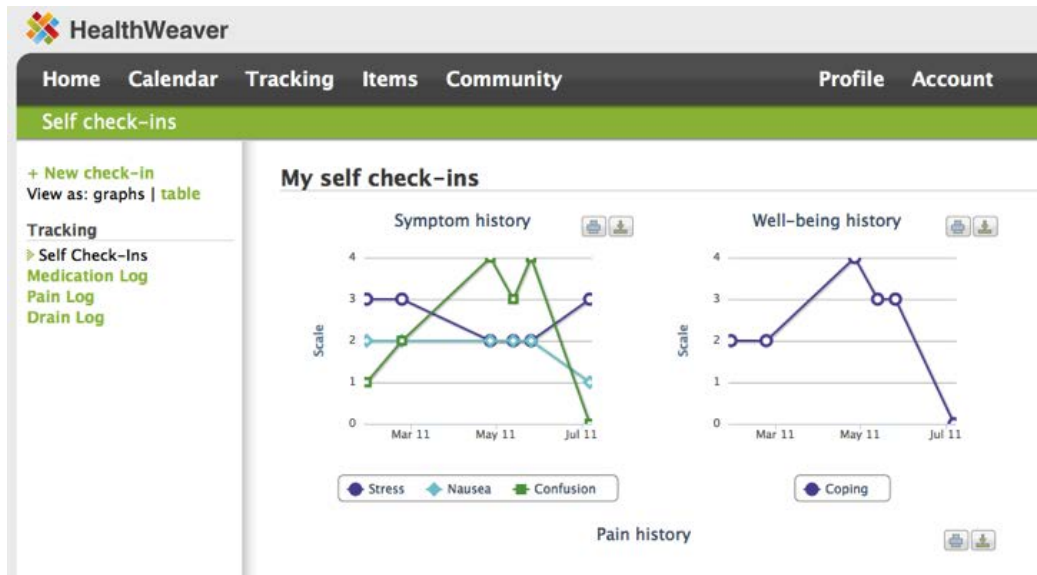
Feature	Overall	EHR	Non-EHR
Scheduling	41% (11)	67%	20%
Patient Portal	19% (5)	33%	7%
Accessible in Non-Cancer Care	44% (12)	58%	33%

- Other Clinical Uses

Feature	Overall	EHR	Non-EHR
Quality Improvement	63% (17)	83%	47%
Patient Satisfaction	37% (10)	58%	20%
Decision Aids	59% (16)	75%	47%
Accreditation Reporting	11% (3)	25%	0%

# System Focus

Audience	Measure Selection	Alert Recipient	Report Access
Clinician	41% (11)	67% (18)	96% (26)
Patient	15% (4)	29% (8)	63% (17)
Staff	--	59% (16)	41% (11)
Caregiver	--	11% (3)	11% (3)



# Discussion

- EHR-integrated systems are more likely to promote fast, integrated PRO use.
- Patient Burden
  - Low rate of user-friendly design
  - Data validity

# Discussion

- **Integration**
  - Overall, score-linked uses are limited.
  - EHR-linked systems show greater integration, but no system does everything.
- **Patient- vs. Provider-Focused Systems**
  - Implications for patient privacy & engagement

# ***Use of PRO Data through the EHR for Outcomes Improvement: An Example from Pediatric Rheumatology***

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PCORI PRO Infrastructure Workshop

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## Background

- Hospital-wide strategic plan initiative to improve outcomes of chronic illness care
- PROs part of metrics of care performance
- Customize EHR with internal IT resources
- Quality improvement (QI) science for reliable implementation, streamlined workflow



## Design to achieve goals

- Which patients?
- Choice of measures?
  - Validity, responsiveness, respondent burden? IP?
  - How often to administer? When? Where?
  - Actionable results? What action will you take?
- Interpretability of PRO scores and reports?

# Engineering for successful adoption

- Pre-requisite: achieve “buy-in” of leadership, providers, staff
- Establish acceptability to patients/providers
- Ensure resources, equipment
- Meet privacy needs of patients
- Design use to minimize clinic disruption

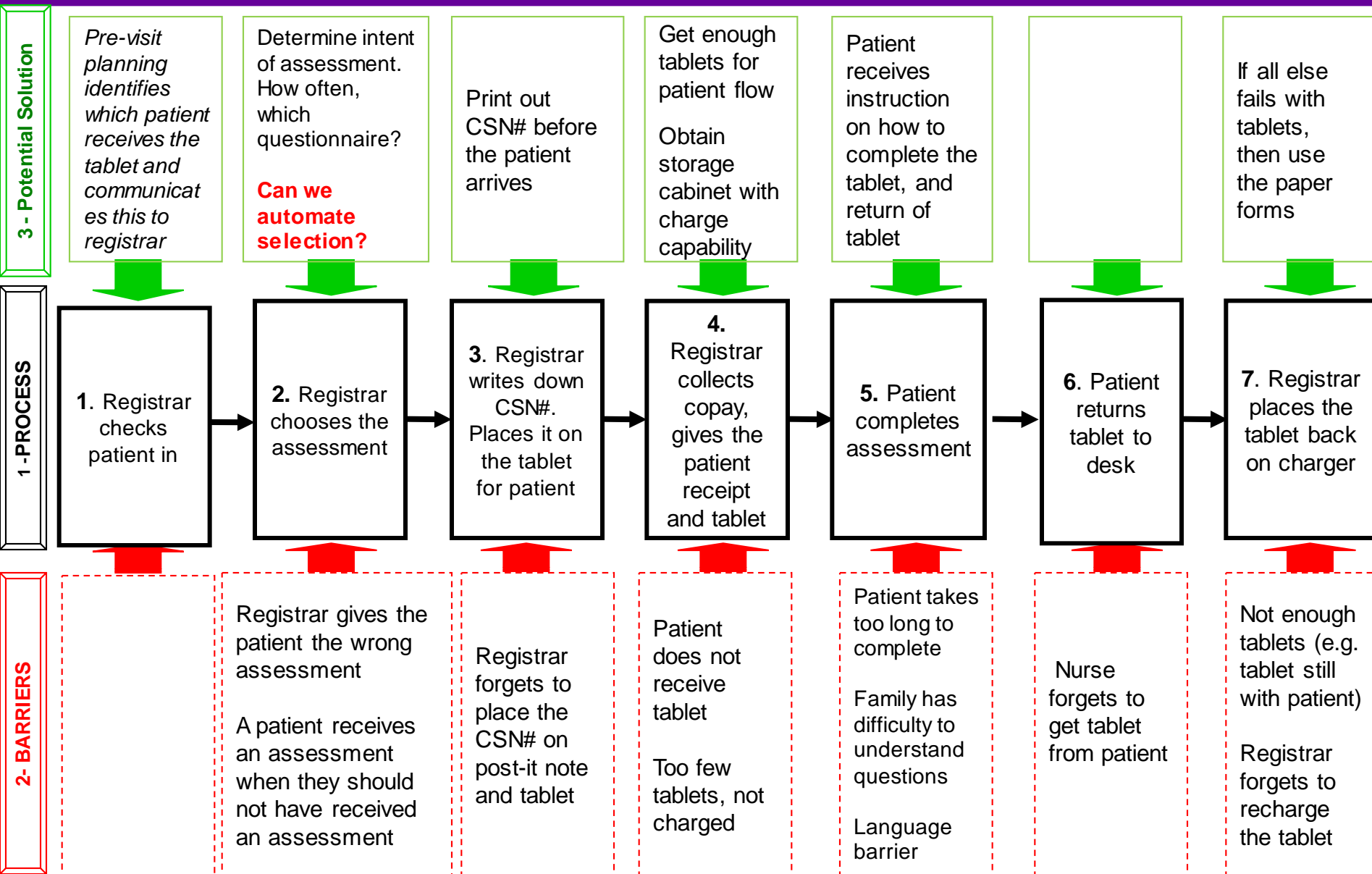
# Role of local context in implementation

- EHR vendor
- Local IT resources
- Ability to integrate PROs into EHR versus use a parallel system (e.g., Assessment Center)
- Ability to customize PRO format and reports
- Clinic characteristics, staffing, flow

## Rationale & Goals

- Current measures of disease status in care of rheumatic diseases have limited use of PROs
- PROs
  - Draw attention to patient concerns
  - Increase patient – provider interaction
  - Ideally drive care management
- Goal to improve clinical care

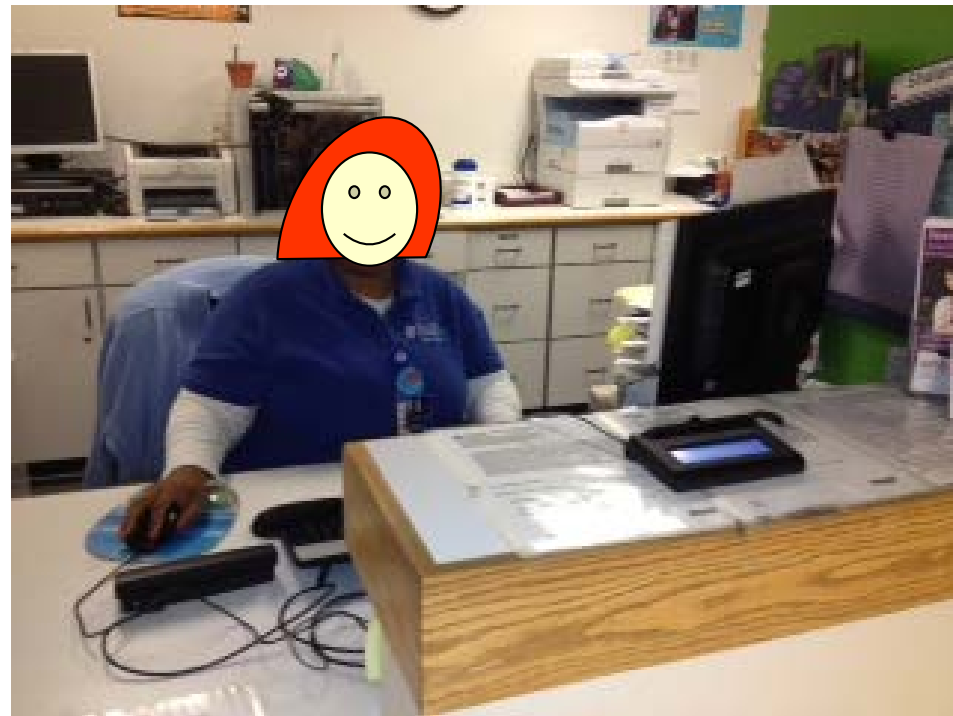
# Failure Modes Effects Analysis\*- Initial PRO Tablet Process



\*simplified

# Automated Questionnaire Assignment

1. Patient is checked in
2. If due, a pop-up shows “a questionnaire needs to be completed”
3. Check-in screen shows list of documents needed [PROs selected based on algorithm]
4. On usual ‘co-pay screen’, clerk may assign the questionnaire
5. After co-pay collected clerk sees “Kiosk Questions” with lists questionnaires to be administered



Patient given “questionnaire ID” to enter into the Tablet and launch relevant questionnaires

Algorithm includes: visit type, age, interval between visits, prior pain score

New patient visit:

Generic HRQoL, Rheum HRQoL

Physical function

PROMIS pain interference short form

Follow-up visit:

Pain interference if intensity score  $>3$

Every 6 mo: physical function,

rheum. HRQoL, pain interference

Every 1 year: generic HRQoL

## Clinic visit

- Selected PROs completed on portable tablets in waiting room or exam room
- Completed items flow real-time into EHR and automatically scored
- Clinician has ability to review scores with patients
- Measures may identify areas of concern not routinely addressed in clinic visits



# Conversion from Paper to Electronic Version – Pain Intensity, Overall Wellbeing, Review of Systems



Division of Rheumatology  
History Intake Form

Patient Name: \_\_\_\_\_  
DOB: \_\_\_\_\_ MRN: \_\_\_\_\_

Date: \_\_\_\_\_

If this is your first visit to our office, please check "Yes" for any items the patient has ever experienced. If this is a follow-up visit, please check "Yes" for any items the patient has experienced since they were last seen in the clinic. If you are unsure about a symptom, please check "Unsure." If the patient has not had a symptom, then check "No." If the patient has symptoms not listed here, please write them in the "Other Symptoms" section.

GENERAL	YES	NO	UNSURE
Tiredness?			
Fever?			
If yes, how many days of fevers have occurred?		_____ days	
How high did the fever go?			°F
Decrease in activities due to physical or medical problems?			
Hospitalized since last visit?			
Days absent from work or school due to physical or medical symptoms?		_____ days	
Weight loss?			
Loss of appetite?			
Difficulty sleeping?			
HEAD, EYES, EARS, NOSE, MOUTH, AND THROAT			
Headache?			
Dry mouth?			
Mouth sores?			
Sore throat?			
Dry eyes?			
Eye pain?			
Red eyes?			
CHEST, LUNGS, AND HEART			
Shortness of breath?			
Chest pain?			
GASTROINTESTINAL SYSTEM			
Heartburn, acid reflux?			
Difficulty swallowing or feeling of food getting stuck?			
Nausea?			
Vomiting?			
Pain or cramps in abdomen?			
Frequent bowel movements?			
Loose stools?			
Vomiting blood?			
Blood in stools?			
GENITOURINARY SYSTEM			
Burning or pain while peeing?			
Blood in urine?			
FEMALES ONLY			
If menstrual periods started, are they regular?			
First day of last menstrual period?		____/____/____	
Pregnant?			
Vaginal ulcers or sores?			
MALES ONLY			
Discharge from penis?			
Rash, ulcers or sores on penis?			

Signature of person completing form: \_\_\_\_\_

Relationship to patient: ☐ Patient/Self ☐ Mother ☐ Father ☐ Other  
If other, please describe relationship: \_\_\_\_\_

BONES, MUSCLES, AND JOINTS	YES	NO	UNSURE
Joint pain?			
Joint swelling?			
Low back pain?			
Muscle pain?			
Neck pain?			
Night pain?			
Weakness of muscles?			
Morning stiffness?			
If stiffness occurs, about how long does it usually last?			_____ minutes
NERVOUS SYSTEM			
Tingling?			
Numbness?			
Seizures or convulsions?			
Nervousness?			
Trouble thinking or remembering?			
Change in personality?			
Depression?			
SKIN			
Hair loss?			
Skin tightening?			
Rash over cheeks?			
White, blue, and red skin color change in fingers on exposure to cold or stress?			
Sun sensitivity (unusual skin reaction, not sunburn)?			
Other rashes?			
Easy bruising?			
OTHER SYMPTOMS:			

## PAIN

We are interested in learning whether or not the patient's illness has caused them any pain?

A) What is the patient's AVERAGE pain score over the past week?

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
No Pain						Very Severe Pain				

B) What is the patient's pain score NOW?

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
No Pain						Very Severe Pain				

## OVERALL STATUS

Considering all the ways that an illness can affect someone, please check the number below that best rates how the patient has been doing on AVERAGE in the past week?

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Very Good						Very Poor				

Printed Physician Name: \_\_\_\_\_  
MD Signature/Credentials: \_\_\_\_\_  
Date and Time: \_\_\_\_\_ Page #: \_\_\_\_\_

## Recent Review Flowsheet Data

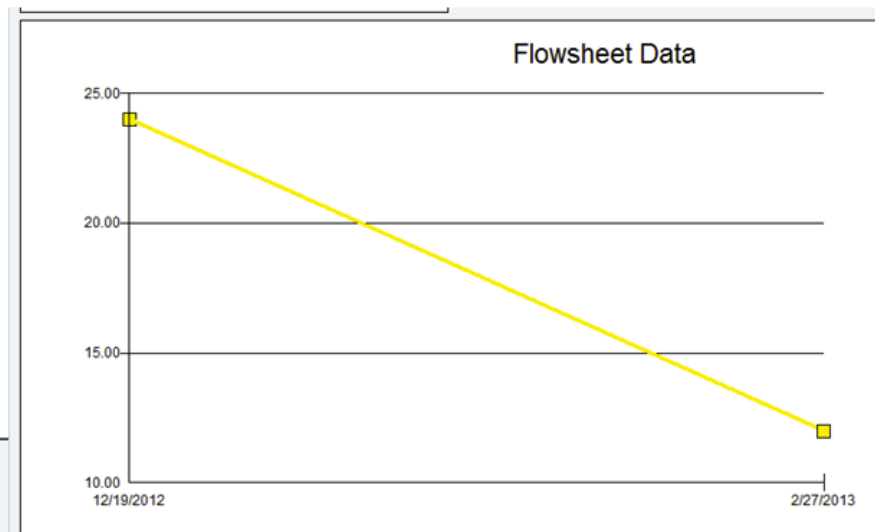
RHE Review of Systems	6/29/
What is the patient's AVERAGE pain score over the PAST WEEK? (Where 0 is No Pain and 10 is Very Severe Pain)	9
What is the patient's pain score NOW? (Where 0 is No Pain, and 10 is Very Severe Pain)	8
Considering all the ways that an illness can affect someone, please select the number below that best rates how the patient has been doing on AVERAGE in the PAST WEEK? (Where 0 is Very Good and 10 is Very Poor)	5
Tiredness?	No
Fever?	No
About how many days have you had your fever?	0
How high did the fever go? (In Fahrenheit)	0
Decrease in activities due to physical or medical problems?	No
Hospitalized since last visit?	No
Days absent from work or school due to physical or medical symptoms?	0
Headache?	Yes
Hair Loss?	No
Dry mouth?	No
Dry Eyes?	Yes
Mouth sores?	Yes
Sore throat?	No
Chest pain?	No
Shortness of breath?	No
Loss of appetite?	No
Weight loss?	No
Numbness?	No
Nausea?	Yes
Pain or cramps in abdomen?	Unst
Loose stools?	Yes
Vomiting blood?	No
Blood in urine?	No

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CCHMC Pediatric Rheumatology

# Display of PRO Items, Responses and Scores – PROMIS® Pain Interference

Pain Interference	12/19/2012	2/27/2013
1. In the past 7 days I felt angry when I had pain.	Sometimes	Never
2. In the past 7 days I had trouble doing schoolwork when I had pain.	Almost Always	Never
3. In the past 7 days I had trouble sleeping when I had pain.	Almost Always	Almost Never
4. In the past 7 days it was hard for me to pay attention when I had pain.	Often	Sometimes
5. In the past 7 days it was hard for me to run when I had pain.	Almost Always	Almost Always
6. In the past 7 days it was hard for me to walk one block when I had pain.	Sometimes	Sometimes
7. In the past 7 days it was hard to have fun when I had pain.	Sometimes	Almost Never
8. In the past 7 days it was hard to stay standing when I had pain.	Often	Sometimes
Pain Interference Score	24	12



● Abnormal/Critical

Dates in: ☒ Columns ☐ Rows

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## Clinic visit – potential pitfalls

- Well accepted by patients, but “form fatigue” develops if too many measures batched in one visit or given too frequently
- Patients need feedback, are results used?
- Technical difficulties may cause frustration
- Computer “down time” requires process for paper PROs

## Uses other than point of care

### Pre-visit planning

- Prior scores on PROs reviewed
  - Impaired physical function or elevated pain interference prompts suggested PT referral
  - Psychosocial red flags prompt social work referral

### Care Coordination

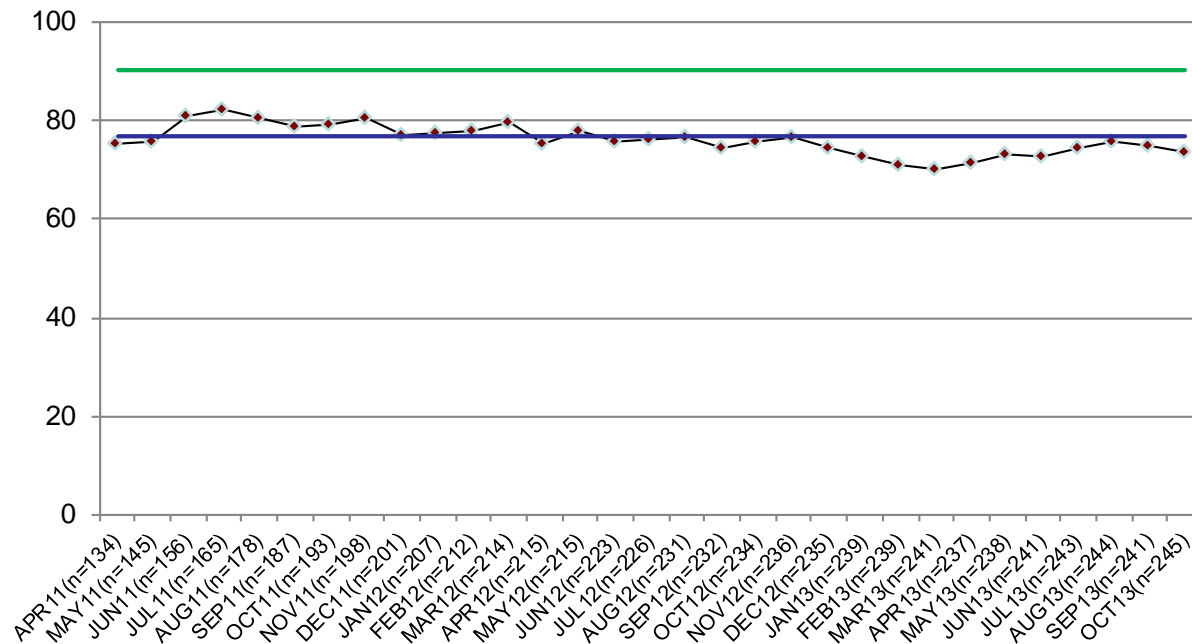
- PRO scores included in “tiering” of patients as part of medical complexity
  - “At risk” assigned a care-coordinator

# Risk Stratification of Patients Includes PRO Scores

Patient's Medical Complexity		
Medications		
Eye disease (Uveitis)		
Comorbidities and complications		
JIA related pain and/or functioning		
Provider global assessment		
Psychosocial Risk Factors		
Illness management & impact (self-management)		
Patient/Family barriers to care		
Safety		
Psychosocial risk factors comments		
Access and Utilization Needs		
Access to subspecialty care		
Access to pediatric healthcare (primary care provider)		
Access to health care (calculated)		
Specialty medical utilization: Frequency of inpatient		
In-home medical services		
Medical utilization (calculated)		
Totals/Tier Level		
Medical complexity total (JIA)		
Psychosocial risk factors total		
Care coordination complexity total		
Total score (JIA)		
Tier level (JIA)		
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# PRO Use for Quality Improvement

## Outcome Measurement - % of patients with average pain score <3



### **Increasing impact of PROs in clinical care**

- Enhance reporting to facilitate provider - patient communication
- Create reference tools to compare scores to population vs condition specific norms
- Establish “MCIDs” (minimal clinical important difference) of PRO measures
  - What change is large enough to act on?
- Train end-users on interpretation and use



## **Increasing impact of PROs in clinical care**

- Decision support
  - Treatment algorithms
  - Potential referrals
  - Patient education materials
- Design for comparative effectiveness research

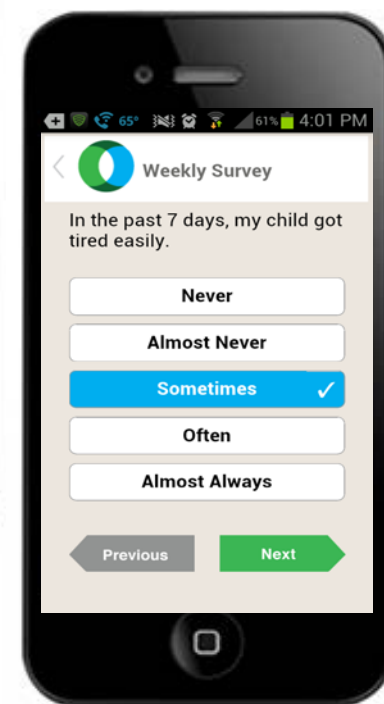


## **Increasing impact of PROs in clinical care**

- Development and dissemination of patient facing reports and tools for patient directed use
  - “Visit Planner App” for patient activation
  - Patient facing reports for self-management
  - Reporting for use in N-of-1 trials

## “Visit Planner App”

- Used throughout the time between clinic visits
- Short weekly assessments using PROMIS items sent via push notification
- Focused visit preparation the week before a visit
- Responses collected, summarize and delivered to parent and team prior to visit



# Summary

- PRO use in clinical care is advancing
- QI approaches may reduce disruption of clinic flow and smooth adoption
- Moving from paper to electronic format is perhaps more efficient, not a “magic bullet”

# Summary

- PRO integration into EHRs and EHR registry data capability will facilitate study of impact of PRO collection on outcomes
- Work remains to design optimal presentation of results for interpretability, training and activation of providers and patients
- Anticipate improvement in patient outcomes with use of PRO data in shared decision making and care coordination

**THANK YOU**