

# Designing an Open-Science Pediatric Learning Health System

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# Goal & Objectives of this Project

## Goal

Develop a prototype for a learning health system in pediatrics focusing on patients with inflammatory bowel disease.

## Objectives

1. EHR-based registry;  
*“Data-in-once → Information-out-many-times”*
2. Quality: population and self management
3. CER: timing of introduction of biologics
4. Sustainability, spread, and governance

# Open-Science Principles for the Learning Health System

Open source software, open notebook, open access to data, open access publications

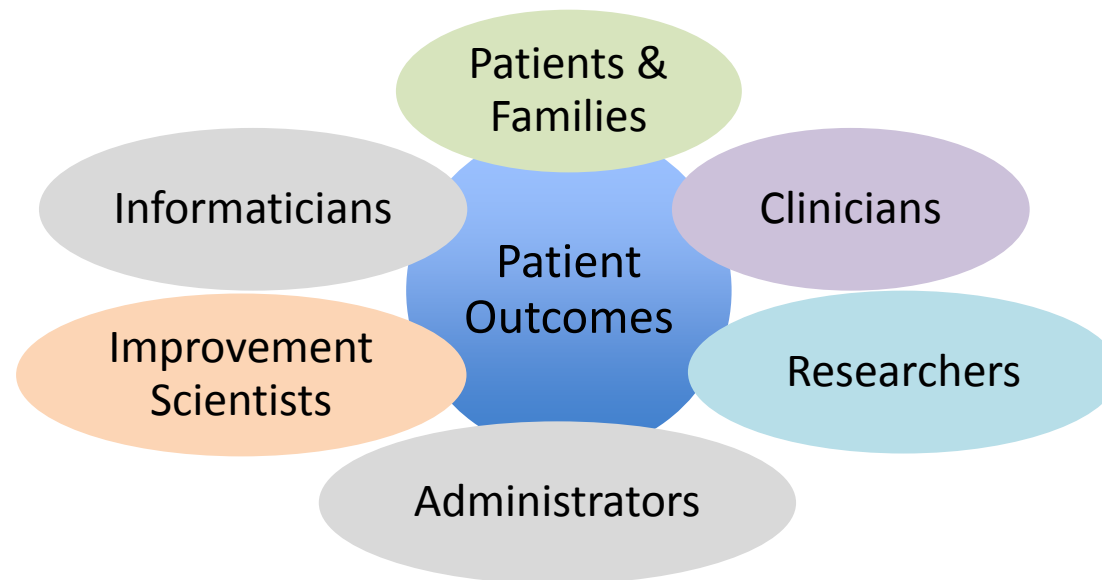
## Benefits

Rapid feedback, collaboration, repurposing, accelerating impact

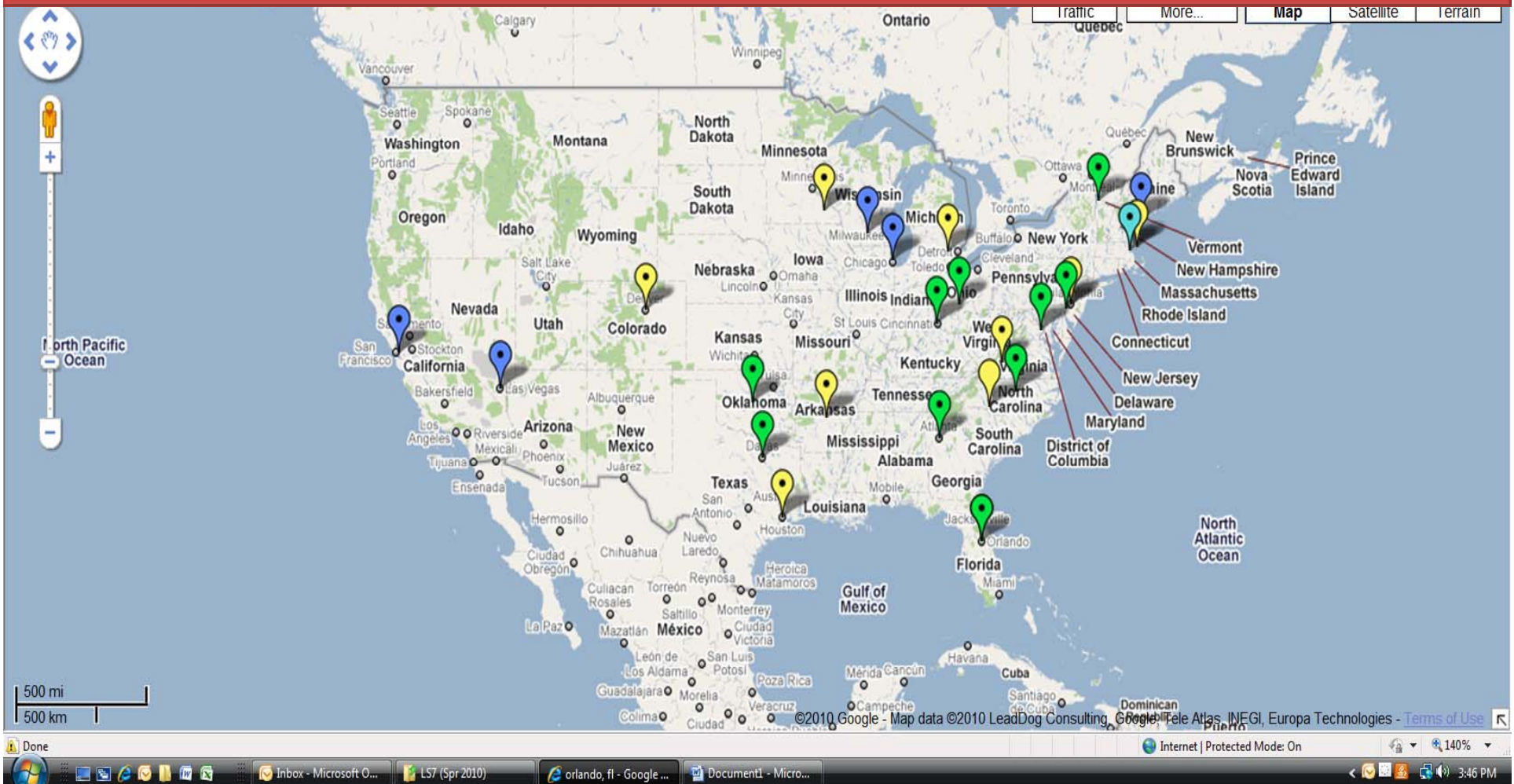


# The Learning Community

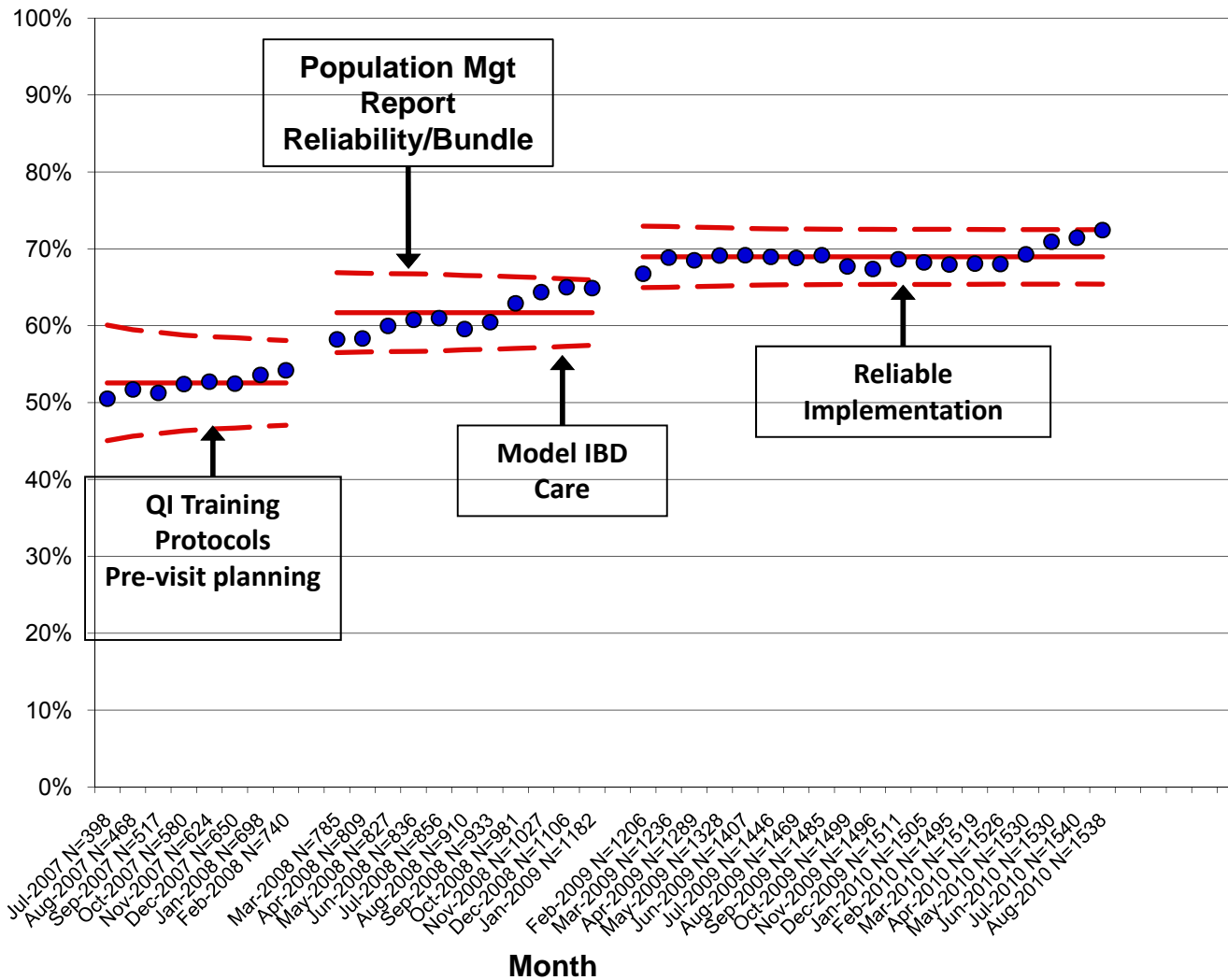
- Pediatric EHR Data Sharing Network (PEDSNet)
  - 15 Children’s Hospitals; 8 participating
- ImproveCareNow – IBD collaborative



# ImproveCareNow: 29 Pediatric GI Practice Sites, from small private groups to large Academic Medical Centers, 270 physicians, and 10,000 children with IBD



# Percent of IBD Patients in Remission (PGA)



A close-up photograph of a human eye with vibrant green irises and dark, well-defined eyelashes. The eye is looking directly forward, and the surrounding skin is a warm, light brown tone. The image is framed by a thin black border.

Focus on the Outcome

## Question

What is the main patient outcome that we are trying to achieve?

## Answer

remission = inactive disease

**Patients  
in  
remission  
>70%**

**Accurate diagnosis  
and disease  
classification**

**Appropriate drug  
selection**

**Appropriate drug  
selection**

**Timing of Biologic  
Agents – an IOM  
Top 100 CER Priority**

**Adequate nutritional  
intake**

**Appropriate growth  
monitoring**

**Registry  
Population Management  
Tool**

**Pre-visit Planning**

**Protocols**

**Auditing**

**Self-Management Support**

# Core Data-Set

## **Process**

Learning community identifies the minimum data-set required to support improvement and analytics

## **Early stages**

Led by clinicians

## **More mature stages**

Full community participates in core data selection

# Pediatric IBD Registry Current State: Data Recorded Three Times



Encounter



Abstraction



Data Entry

# Data-In-Once Requires Changes to the EHR User Interface

**IBD Smart Form**

Assistant (patient reported information)				Practitioner (evaluation and management)			
Age at Dx (dec yrs)	8.4	IBD Type:	Crohn's	Ulcerative Colitis Stage		Last ophth exam	
PSH	ADENOTONSILLECTOMY UNDER 12 TYMPANOSTOMY, GENERAL ANES	Adenot		Crohn's Vienna L score	L3 ileocolonic	LMP	N/A
Pat Centered Info				Crohn's Vienna B score	B3 penetrating	Tanner	3
				Hx of Perirectal Disease	skin tags		
				PPD Status			

Score legend  
 1 Impact III  
 2 PCDAI  
 3 SCCAI  
 Scores

Has past medical history and SH been updated?

Subjective | Adherence | Nutrition | Nutritional Assessment | Objective | Assessment & Plan | PCDAI

History of Present Illness

Chief Complaint CROHN'S DISEASE

Course/General well being: 23 slightly below par

Interrupted/ missed out 12 rarely

Abdominal Pain 2 no abdominal pain

Bowel Frequency (Day) 3 2 per day

Bowel Frequency (Night) 3 none at night

Urgency of defecation 3 need to hurry

Blood in stool 3 trace

APPETITE: 1 sometimes

ATTENDED SCHOOL: 1 most of the days

MISSED SPORTS: 1 sometimes

Extraintestinal manifestations 23  None  All 'No'

Erythema nodosum Yes Joint pain Mouth sores Growth failure Pancreatitis

Pyoderma gangrenosum Uveitis Fever Delayed puberty Liver disease

Describe Intestinal/ROS  
 Erythema nodosum, uveitis, fever and growth failure were reviewed. Extraintestinal manifestation found was erythema nodosum.

SCCAI Score  
 7  
 5  
 Calculate

Stool consistency solid

Tenesmus tenesmus

Unscheduled visits since last appt  
 ER 0  
 Office / ill call 1  
 Hospital 0

Additional HPI None

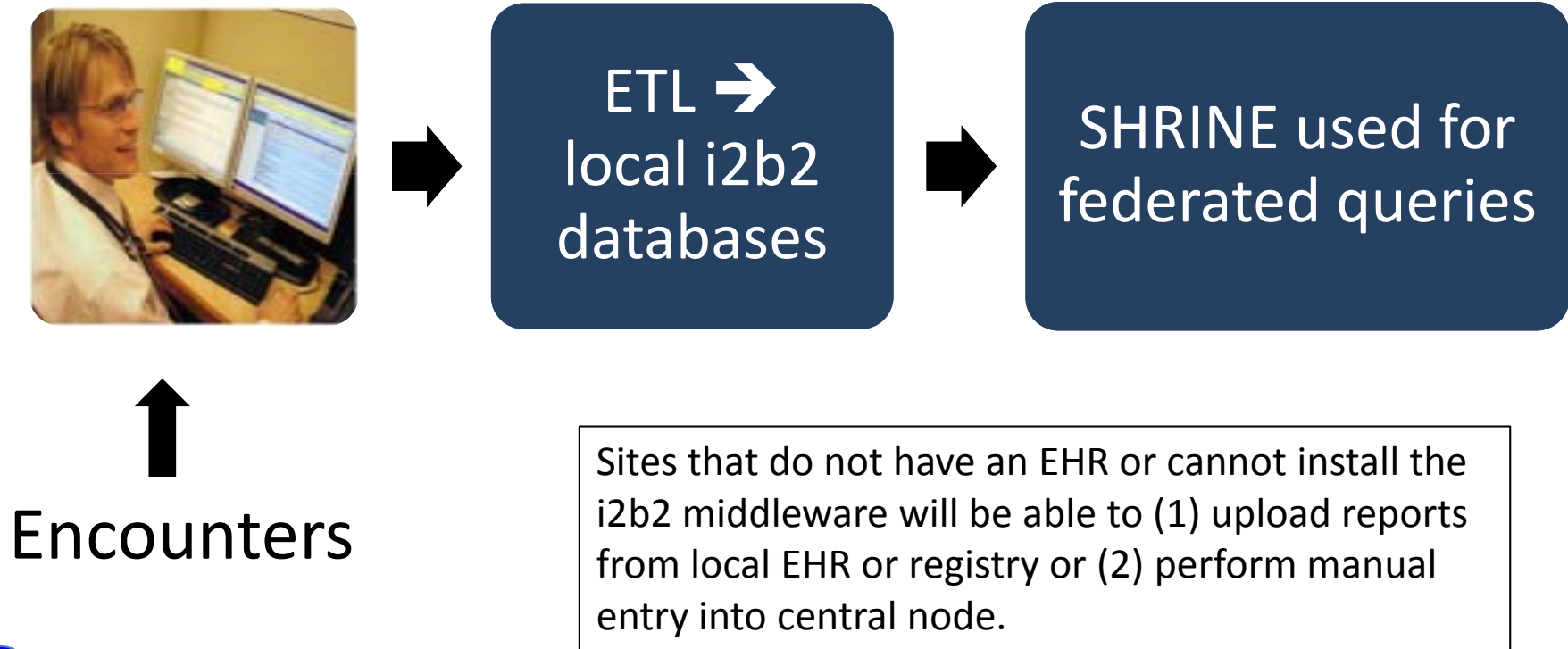
"504" filled out? Yes No  
 Alternative/complementary medicine? Yes No  
 Drugs/alcohol use? Yes No  
 Sexually active? Yes No

Form legend  
 Assistant  
 Pulled  
 Calculation  
 Entry

A collaborative of Nemours Clinical Management Program (NCMP)

Cancel Accept

# Pediatric IBD Registry Future State: Data-in-Once, Automated ETL Processes, Federated Queries



## Five Adaptive Treatment Strategies for Children with Newly Diagnosed Crohn's Disease

Newly Diagnosed  
Children with  
Crohn's Disease

Top-Down Biologics: Anti-TNF $\alpha$  at diagnosis

Rapid Step-Up to Biologics: Thiopurines/Steroids  $\rightarrow$   
Anti-TNF $\alpha$  within 6 months

Late Step-Up to Biologics: Thiopurines/Steroids  $\rightarrow$   
Anti-TNF $\alpha$  6-12 months

Thiopurines Only: Thiopurines/Steroids only

No Biologics/Thiopurines: Steroids only or no systemic  
therapy

# Modified Delphi: Clinical Factors that Affect Choice to Use Biologics

Clinical Factor	Mean Importance Rating (1-10)
Fistulizing/penetrating disease	9.5
Disease severity/activity	9.0
Failure to respond to TPs/Steroids	9.0
Perianal disease, including fistulas	8.8
Steroid dependence/resistance	7.5
SEs of other medications	6.9
Growth failure	6.9
Extensive small bowel disease	6.4
Stricturing disease	6.2

# Adding Patient Reported Outcomes

- Adding a PRO measurement System using NIH's PROMIS Network
- Patients/Parents will go to web site to complete PROMIS computerized adaptive tests before/after and encounter
- The LHS community will design this system



# Accelerating Knowledge Impact with a Learning Health System

