



SPRING 2021 COMMUNITY CONFERENCE  
**STRONGER TOGETHER**

Reflection, Resilience, and Recovery

March 25 - 26, 2021 #ICNCC21S

## IMPROVECARENOW Spring 2021 LIVE ONLINE COMMUNITY CONFERENCE

Refer to the following list of options as you decide which breakout sessions to attend at the ImproveCareNow Spring 2021 Live Online Community Conference.

Consult with colleagues attending from your center (including parent and patient partners) to maximize your team's exposure to these sessions—plan to divide and conquer! Please contact [info@improvecarenow.org](mailto:info@improvecarenow.org) with any questions about these breakouts.

**Thursday, March 25**

### 12:35 PM EDT Community Proposed Breakouts I

**Clinical: Obesity and Inflammatory Bowel Disease**

- Inflammatory Bowel Disease (IBD) has been historically associated with underweight and malnutrition, however rates of obesity have been rising in patients with IBD, similar to the general population.
- Children with IBD can either present with the co-morbidity of obesity or develop during their course of treatment.
- ImproveCareNow looked at around 1600 children with IBD and found that 14.1% were overweight and 9.5% were obese.
- The goals of our project were to assess the practices of screening for metabolic diseases associated with obesity in children with IBD and to improve the management for these patients.

**IRB: Playing Common Rule Jeopardy: What is 45 CFR part 46?**

- A discussion between Cincinnati Children's Director of ORCRA, Jeremy Corsmo and Dr Peter Margolis, Scientific Director for ImproveCareNow about important changes in the new Common Rule and its implications for helping patients and families understand how data are used in the network.

**Psychosocial: Mental Health Screening and Intervention: Reflection, Resilience and Recovery**

- Summarize the ICN Strategic Plan for prioritizing patient-reported outcomes (PROs) and mental health
- Share ICN patient perspectives regarding mental health screening
- Summarize the prevalence of mental health concerns in pediatric IBD
- Highlight the COVID pandemic's impact on mental health needs in youth and families
- Provide examples of telehealth applications of mental health screening

**Engagement: The Importance of Advocacy for Patients, Families, and the Community Recovery**

- Have ideas of how to get involved in local/national patient advocacy groups (PAC, or other)
- Understand the importance of advocacy in different settings
- Better self advocate in medical, education and employment situations

**Research: PRODUCE Study: A Multicenter Dietary Intervention Study within a Learning Health Network- Lessons, Reflections, and Practical Suggestions**

- Review the design and advantages of N-of-1 trials
- Highlight the individual trial and population level results to determine the effectiveness of a specific carbohydrate diet (SCD) in reducing symptoms and inflammatory burden in patients with IBD versus a modified SCD
- Clarify impact and understanding of diet in IBD
- Demonstrate the value of a multidisciplinary team, including design, implementation and data analysis during execution of a research study

**Thursday, March 25**

### 2:25 PM EDT Community Proposed Breakouts II

**Clinical: IBS in IBD**

- Discuss the impact of functional disorders on IBD patient quality of life, even when in clinical remission. Patient perspectives on symptom management, strategies for discussion of topic in clinic, and input from clinicians.

**Psychosocial: Managing Mental Health and IBD during the COVID-19 Pandemic**

- Cover patient perspectives on the impact of isolation during the COVID-19 pandemic
- Highlight both potential gaps and opportunities within the nexus of mental health resources

**Thursday, March 25**

**2:25 PM EDT Community Proposed Breakouts II (continued)**

**QI: Utilization of an IBD Dashboard to Improve Process (PVP, Scheduling, Monitoring, etc.) and Outcomes**

- Illustrate effectiveness of interactive disease-specific dashboard in facilitating the PVP process
- Demonstrate ability to utilize a dashboard to improve care coordination
- Highlight the role the dashboard plays in population management- focusing on disease severity measures
- Showcase utilization of the dashboard to track various measures
- Demonstrate utilization of dashboard to promote early disease control

**Research: Investigator Initiated Studies**

- Initial therapy in newly diagnosed pediatric Crohn's disease in the biologic era: Data from the ImproveCareNow (ICN) network.
- A data-driven approach for risk stratification and outcome prediction for Pediatric Inflammatory Bowel Disease

**Nutrition: Use of the Crohn's Disease Exclusion Diet within the ICN Community**

- Understand how the CDED is being implemented across the ICN community and identify opportunities for future QI projects related to this diet therapy and improving patient outcomes

**Friday, March 26**

**11:25 AM EDT Community Proposed Breakouts III**

**Clinical: Identification and Treatment of Iron Deficiency Anemia in Pediatric Inflammatory Bowel Disease- A Quality Improvement Initiative**

- Overview of NASPGHAN guidelines related to iron deficiency and iron deficiency anemia
- Overview of two QI initiatives to improve iron deficiency and iron deficiency anemia in IBD

**QI: Food Insecurity Screening in GI Clinic: Why it is Important and How to Start**

- Understand the importance of food insecurity screening for IBD patients

**Psychosocial: Recovering from Flares**

- Review the physical and mental aspect in recovering from a flare and to evaluate available resources (such as dietary guidelines)
- Give insight on the recovery process including what to expect and how patients can get support
- Assist patients and families in understanding what their loved one is going through during recovery and how that might shape social and personal interactions

**Technology: Collaborative Tools to Drive Outcomes: ICN Hub and New Registry**

- Participants will be able to identify three features of ICN Hub which they wish to explore further and three ways to get help or give feedback on ICN Hub
- Participants will see an overview/demo of the new ICN Registry interface and some features. At the conclusion of this activity, the participants will be able to describe how to access the new ICN Registry, explain improvements compared to the current registry, and know where to ask questions or give feedback in the [ICN New Registry Feedback group on ICNHub](#).

**Research: Overview of ICN Research for the Community**

**12:10 AM EDT Community Proposed Breakouts IV**

**Clinical: SEMA-CD, the New Pediatric Crohn's Disease Colonoscopy Score**

- Provide background on colonoscopy scores
- Introduce the new pediatric SEMA-CD colonoscopy score
- Illustrate ease of use of SEMA-CD for clinicians
- Show how SEMA-CD will help with clinical care and improve future research

**QI: QI and Autoimmune Liver Disease (AILD): Lessons Learned from ICN to Improve Outcomes in Pediatric Liver Disease**

- Gain insight into how the liver may be impacted in children and adolescents with IBD and implications for diagnosis and management
- Understand the connections between ICN and A-LiNK including centers in the A-LiNK pilot, development of parent community and goals for improved outcomes

**Technology: myICNhome: Pilot Resource for the Newly Diagnosed**

- Review the process to coproduce *myICNhome*
- Share the new online community commons, highlighting the valuable resources and tools for patients and families

**Engagement: Resilience, Vulnerability and Validation Part 2**

- Learn what resiliency, vulnerability, and validation mean from a patient perspective
- Highlight what vulnerability looks like in a patient-provider relationship in order to promote resilience

**Data: Data Quality Scorecard in Action: Analyzing Your Data and Improving the Process**