Adherence Breakout
Friday 9:10
Agenda

- Welcome and Introductions- 10 minutes
- Sustained Remission Definition Update- 15
- Pathway to Mastery/ LL Progress- 10 minutes
- Prework Discussion- 20
- Wrap up/framing of opportunity for screening of barriers- 5 minutes
Breakout Session Leaders

Kevin Hommel, PhD
Cincinnati Children’s Hospital Medical Center
(via phone)

Michele Maddux, PhD
Children’s Mercy

Marc Tsou, MD
Children’s Hospital of The King’s Daughters

Kate Harrow
Cincinnati Children’s Hospital Medical Center

Julie Massie
Cincinnati Children’s Hospital Medical Center
Adherence Care Centers

1. Where are you from?
2. Who is here today?
3. What role do you play with helping patients with adherence?

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Location</th>
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<tbody>
<tr>
<td>Boys Town National Research Hospital</td>
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<tr>
<td>Children’s Hospital and Medical Center Omaha</td>
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<tr>
<td>Children’s Hospital at Dartmouth</td>
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<tr>
<td>Children's Hospital of Illinois, Univ of Illinois Peoria</td>
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<tr>
<td>Children’s Hospital of the King’s Daughters</td>
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<td>Children’s of Alabama</td>
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<td>Kravis Children’s Hospital at Mount Sinai</td>
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<tr>
<td>NY Presbyterian- Komansky Children’s Hospital at Weill Cornell</td>
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<tr>
<td>Phoenix Children’s Hospital</td>
<td></td>
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<tr>
<td>UF Health Pediatric Gastroenterology, Hepatology &amp; Nutrition</td>
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<tr>
<td>University of New Mexico Children’s Hospital</td>
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</tbody>
</table>
Sustained Remission Definition Update
Pathway to Mastery
Learning Lab Progress
### Learning Lab AIM

<table>
<thead>
<tr>
<th>Learning Lab</th>
<th>AIM</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fundamentals</strong></td>
<td>Achieve site activation &lt; 90 days (IRB reliance, PDUA executed)</td>
</tr>
<tr>
<td>Register &gt; 75% of IBD populations &lt; 9 months of site activation</td>
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</tr>
<tr>
<td><strong>Reinforcing</strong></td>
<td>Register &gt; 75% of IBD populations &lt; 9 months of joining learning lab</td>
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### Learning Lab AIM

<table>
<thead>
<tr>
<th>Learning Lab</th>
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</thead>
<tbody>
<tr>
<td>Multidisciplinary Pre-Visit Planning</td>
<td>Increase the percentage of centers reliably implementing established PVP process to ≥90% by March 2020</td>
</tr>
<tr>
<td>Population Management</td>
<td>Increase population management reliability from X% - 90% by March 2020</td>
</tr>
</tbody>
</table>

March 2019: Learning Labs established at the ICN Spring 2019 Community Conference.
April 2019: Centers selected Pathways and Learning Labs
May 2019: 3 Pathway Kick off meetings hosted
June 2019: 6 Learning Labs began

### Learning Lab AIM

<table>
<thead>
<tr>
<th>Learning Lab</th>
<th>AIM</th>
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</thead>
<tbody>
<tr>
<td><strong>Adherence</strong></td>
<td>By addressing barriers, participating centers will optimize therapy and treatment adherence to increase the % of IBD patients in sustained clinical remission from x% to 70% by March 2020</td>
</tr>
<tr>
<td><strong>Clinical Standardization / Personalized Care</strong></td>
<td>Participating centers will develop and standardize care pathways to increase the % of IBD patients in sustained clinical remission from x% to y% by March 2020</td>
</tr>
</tbody>
</table>
Pathway To Mastery Steering Team

Foundations
>75% Registered Patients

Achieving Remission
>82% Remission

Achieving Sustained Remission
>55% Sustained Remission

Trailblazers
>75% Sustained Remission

Fundamentals
N= 16 centers

Multidisciplinary Pre-Visit Planning
N= 10 centers

Adherence
N= 11 centers

Clinical Standardization/ Personalized Care
N=27

Reinforcing Foundations
N=14 centers

Population Management
N= 25 centers

Engagement
N= TBD; Launching CC Fall19

Research
N= TBD; Launching CC Fall19

Auto-immune Hepatitis (AIH) and Surgery; Launching 2020

Engagement  |  Psychosocial Support  |  Nutrition

Regional Meetings (NE Regional Meeting November 7-8, 2019)
Global Aim

Improve the care and health of all children and adolescents with Crohn's disease and ulcerative colitis.

SMART Aim

SREM Pathway Aim: Increase the % of IBD patients in the ICN registry in sustained clinical remission from x% to y% for centers participating in the sustained remission pathway by March 2020.

Improved quality of life: TBD LL

AIM: By addressing barriers, participating centers will optimize therapy and treatment adherence to increase the % of IBD patients in sustained clinical remission from x% to >=70% by March 2020.

Population

Participating ICN centers in the Sustained Remission pathway with patients in the ICN registry

Key Drivers

- Optimal access and communication with multidisciplinary IBD care team
- Proactive, timely reliable, planned care and population management and treatment pathways standardized by disease severity
- Patient centered, shared decision making around treatment and outcome goals
- Consistent screening for adherence risk
- Optimal nutritional intake and diet adherence
- Optimal psychosocial health
- Reliable medication adherence including biologics
- Adherence to clinic visits
- Reliable self-management support bundle implementation
- Parent and patient engagement through co-production

Interventions

- **Team Leadership**
  - Reliable implementation of the Foundations Key Driver Diagram
  - Alignment on Sustained Remission Definition

- **Reliable implementation of the Remission Key Driver Diagram**
  - Consistent Reliable Care
  - Population Management (PM)
  - Pre-visit Planning (PVP)

- **Use of technology for communication and monitoring of treatment compliance (data collected from an app)**

- **Patient centered barriers assessment**

- Defined barriers assessment

- **Established criteria for consult/referral**

- Multidisciplinary resources available real time during clinic for consult (SW, Dietitian, etc.)

- **Consistent process to schedule and follow up on appointments, LABS AND PRESCRIPTIONS**

- **Self-Management Support (SMS)**
  - Reliable implementation of the Remission Key Driver Diagram
  - Encourage lifelong journey of education; **JOURNEY BOARD, TRANSFER TOOLKIT**
  - Clarify symptoms and when to call health care team
  - Visit frequency compliance
  - Shared treatment and outcome goals; **PATIENT PAMPHLET; BARRIERS DISCUSSION**
  - Peer to Peer engagement/PAC and PWG participation

- **Engagement and Coproduction**
  - Active participation and contribution by parents and patients
  - QI training and support- QI Fundamentals, Webinars
  - Communications- Newsletters, SLACK, Circle, Social Media
  - Engagement Infrastructure- Communication, Events and Team

James M. Anderson Center for Health Systems Excellence
Pathway to Mastery SharePoint Site

Our mission is to transform the health, care, and costs for all children and youth with Crohn’s disease and ulcerative colitis by building a sustainable collaborative chronic care network, enabling patients, families, clinicians and researchers to work together in a learning health care system to accelerate innovation, discovery, and the application of new knowledge.
Percent of patients in sustained clinical remission, PGA
Prework Learnings
Understanding Barriers
Adherence Learning Lab: Community Conference Pre-Work

Instructions: Select 1-2 weeks of patient appointments to review (can be prospective or retrospective) and answer the questions associated with each process step below. Document your observations and learnings by using tally marks to indicate how many times the following situations occurred during the time period you are reviewing.

<table>
<thead>
<tr>
<th>Step 1: Pre-Visit Planning</th>
<th>Step 2: Patient Appointment</th>
<th>Step 3: Patient Visit Completed</th>
<th>Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How many patients are scheduled for the time period you are reviewing?</td>
<td>• How many patients attended their scheduled visits for the time period you are reviewing?</td>
<td>• How many patients did not schedule a follow up appointment before leaving?</td>
<td>• What observations or learning opportunities did you identify for each process step?</td>
</tr>
<tr>
<td>• How many patients did not fill prescriptions as intended?</td>
<td>• How many patients did not show for their scheduled appointment?</td>
<td>• How many patients did not schedule follow up labs before leaving?</td>
<td>• How many patients were screened for barriers to adherence out of the total number of patients scheduled for the time period?</td>
</tr>
<tr>
<td>• How many patients needed labs prior to this visit and did not get labs?</td>
<td>• How many patient visits did not have barriers to adherence addressed? (consider medication management, labs, infusion appointments, etc.)</td>
<td>• How many patients do not have a recommendation for follow up care to address an identified barrier?</td>
<td>• What opportunities do you see for enhancing communication within your clinic’s multidisciplinary team?</td>
</tr>
<tr>
<td>• How many patients have incomplete information in record (missing external labs, etc.)?</td>
<td>• How many patients were screened for barriers?</td>
<td></td>
<td>• What information is important to your clinic that is not currently captured through your process? Why is it important and how would you capture it?</td>
</tr>
<tr>
<td>• How many patients had an identified adherence barrier at their last visit that needs addressed at the upcoming appointment?</td>
<td>• How many patients did not have identified barriers addressed during this clinic visit?</td>
<td></td>
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</tr>
</tbody>
</table>
Understanding Barriers

- Opportunity to standardize our assessment of barriers
- Add parents and patients to our teams
- Build upon the Chronic Care Model
  - Community Resources and Policies
  - Self Management
  - Health System Support
  - Productive Interactions
Adherence Breakout
Saturday 8:45
Agenda

- Welcome/review agenda- 5 minutes
- SREM Definition Update- 10
- Screening for Barriers: The Opportunity- 10 minutes
- Introduction of ICN Screening for Barriers tool- 10 minutes
- Team time- develop plan to implement screening on at least 5 patients- outline process map and PDSA-25 minutes
- Report out- 10 minutes
- Next steps- upcoming webinars- 5 minutes
SREM Definition Follow Up
Screening for Barriers: The Opportunity
Screening for Barriers

- ICN background
  - Medication Adherence Experience
- ICN opportunity
  - Expand to screening barriers
  - Modify existing evidence-based tools
  - Standardize approach and assessment
  - Use QI to incorporate screening and follow up in clinic visit
Screening for Barriers Tool
Parent/Caregiver Barriers Survey

Instructions: Circle the item number if the item is a barrier to you or your child.

Medication Barriers
1. My child has a hard time swallowing pills (medication, vitamins, supplements) or administering the medication (i.e., subcutaneous injection, injection) to himself/herself
2. My child has too many medications to take
3. My child does not like how the medication tastes
4. My child feels that it gets in the way of his/her activities
5. My child is forgetful and doesn’t remember to take his/her medication every time
6. My child is not very organized about when and how he/she takes his/her medication
7. My child does not want other people to notice him/her taking the medication
8. My child is very busy with other things that get in the way of taking the medication
9. My child sometimes feels too sick to take the medication
10. My child finds it hard to stick to a fixed medication schedule
11. My child doesn’t like what the medication does to his/her appearance
12. My child is tired of living with IBD
13. I am not always there to remind my child to take his/her medication
14. My child believes the medication has too many side effects
15. My child relies on me to remind him/her when to take his/her medication
16. My child is tired of taking medication
17. It is difficult to keep track of when to get refills, so my child doesn’t run out of medication
18. Sometimes it is hard to make it to the pharmacy to pick up the prescription (or order from an online pharmacy) before the medication runs out

Is there anything else that we did not mention that makes it hard for your child to take his/her medication on schedule every day?

Medical/Laboratory Appointment Barriers
1. I am not aware of how often my child should be seen by a physician.
2. I do not know how to schedule a medical or lab appointment for my child.
3. I need to schedule appointments that work for other people (spouse, partner, caregiver) who help with my child’s care
4. I am not aware of what labs my child needs to have done or how often they need to be done.
5. I do not understand why the labs are important to my child’s care.
6. I do not know where I need to go to have my child get their lab work completed.
7. I don’t / my child doesn’t like the pain the lab draws cause.
8. I do not have reliable transportation to get to and from appointments.
9. My job/work hours can make it hard to schedule or attend appointments.
10. Finding someone to watch my other child(ren) is a challenge.
11. I feel I cannot afford the cost for my child’s appointments and lab visits.
12. If my child feels okay, I don’t think I need to attend a scheduled appointment.

Is there anything else that we did not mention that makes it hard for your child to attend scheduled medical or laboratory appointments?

(Continue to next page)

Parent/Caregiver Barriers Survey- 2 pages
Developed with permission from L. Simons- Parent Medication Barriers Survey and Adolescent Medication Barriers Survey
Instructions: Circle the item number if the item is a barrier to you.

Adolescent Medication Barriers Survey

1. I believe that it is hard to swallow pills or give myself an injection/shot
2. I believe that I have too many different medications to take
3. I don’t like how the medication tastes
4. I believe the medication has too many side effects
5. I don’t want to take the medication at school
6. I feel that it gets in the way of my activities
7. I am forgetful and I don’t remember to take the medication every time
8. I am not organized about when and how to take the medication
9. I do not want my friends or other people to notice me taking the medication
10. I sometimes just don’t feel like taking the medication
11. I find it hard to stick to a fixed medication schedule
12. I don’t like what the medication does to my appearance
13. I am tired of taking medication
14. I am tired of living with IBD
15. It is difficult to keep track of when to get refills, so I don’t run out of medication
16. I get confused about how the medication should be taken (with or without food, with or without water, etc.)
17. Sometimes it is hard to make it to the pharmacy to pick up the prescription (or order from an online pharmacy) before the medication runs out

Is there anything else that we did not mention that makes it hard for you to take your medication on schedule every day?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________
Feedback

- Based on your prework, how will this screening tool help mitigate failures you have identified?
- How can you incorporate this screening tool into your clinic visits?
  - What roles will be required?
  - How will the paper follow the patient through the visit?
  - Are there limitations with how the tool has been designed?
Develop a Process Map

- With your team, begin to outline the process to incorporate the Screening for Barriers tool into your clinic
- Consider roles and responsibilities:
  - How will you identify patients?
  - Who will introduce the tool(s) to the family?
  - What talking points will be used?
  - Who will give the information to the provider?
  - How will information be included in the clinic visit?
  - How will you partner with other disciplines (dietitians, social workers, psychologists, etc.)
Screening for Barriers Simplified Failure Mode Effects Analysis (sFMEA©)

**Pre-Visit Planning**
Clinic huddles to identify which patients will participate

**Identify Patients**

**Give Screener to Parent/Patient**

**Collect and review Screener**

**Give Screener to provider prior to going into visit**

**Provider discusses barriers identified**

**Additional resources are identified**

Nurse collects Screener from family when rooming patient and reviewing vitals. Check for completeness and clarifying questions

Standardize location for completed documents

Multidisciplinary team members are alerted

Next steps are incorporated into clinic note

Clinic note is updated with plan of care

Resources are compiled

Multidisciplinary team members are involved

**Standarize talking points**

**Front desk gives Screener to family**

**Standardize** location for completed documents

**Multidisciplinary team members are alerted**

**Nurse collects Screener from family when rooming patient and reviewing vitals. Check for completeness and clarifying questions**

**Give Screener to provider prior to going into visit**

**Provider discusses barriers identified**

**Additional resources are identified**

**Identify Patients**

**Give Screener to Parent/Patient**

**Collect and review Screener**

**Give Screener to provider prior to going into visit**

**Provider discusses barriers identified**

**Additional resources are identified**
Measures of Success

Process:

• % of patients seen in the last month with Screening for Barriers documented in chart

• % of barriers identified by type (by parent and by patient)
What can you do by next Tuesday?

- Create a PDSA to test the Screening for Barriers tool with at least 1 parent/caregiver and 1 patient.
- Develop a PDSA ramp to expand testing to at least 5 patients.
- Considerations:
  - When will you start the PDSA?
    - How will you communicate the test to the team?
    - How will you know which patients receive the Screener and which don’t?
PDSA Worksheet – <Project Name> – <Intervention>

Project SMART Aim: Type here

What key driver does this test impact? Type here

What is the objective of the test? Type here

PLANNING:

A. Briefly describe the test:
Type here

B. How will you measure the success of this test?
Type here

C. What would success look like?
Type here

D. What do you predict will happen?
Type here

E. Plan for collection of data:
Type here

F. Tasks:

<table>
<thead>
<tr>
<th>List the tasks necessary to complete this test (what)</th>
<th>Person responsible (who)</th>
<th>When</th>
<th>Where</th>
</tr>
</thead>
<tbody>
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DO:
Test the changes.
Was the cycle carried out as planned? ☐ Yes or ☐ No

Record data and observations.
Type here

What did you observe that was not part of the plan?
Type here

STUDY:
Did the results match your predictions? ☐ Yes or ☐ No

Compare the result of your test to your previous performance:
Type here

What did you learn?
Type here

ACT:
Decide to Adapt, Adapt or Abandon (shade one box).

☐ Adapt. Improve the change and continue testing the plan.
Plan/changes for next test:
Type here

☐ Adopt. Select changes to implement on a larger scale and develop an implementation plan and plan for sustainability.

☐ Abandon. Discard this change idea and try a different one.
## Ramp Strategy Planning

*To be completed prior to beginning PDSA testing

<table>
<thead>
<tr>
<th>Test Description:</th>
<th>Test Cycle 1</th>
<th>Test Cycle 2</th>
<th>Test Cycle 3</th>
<th>Test Cycle 4</th>
</tr>
</thead>
</table>

| Test Population (description & n=._): | | | | |

| Location of test: | | | | |

| Duration (# hours/days/shifts/etc.): | | | | |
• Identify one person from your center to share your process map and PDSA draft
• What idea can you ‘steal’ from another center and test?
• What areas have challenges?
Next Steps by October 18th

- Email your completed process map incorporating the barriers screening tool, your PDSA worksheet and PDSA ramp to info@improvecarenow.org.
- Implement your PDSA- goal is to test with 5 patients
  - Guidance: Give parent/caregiver the screening tool as noted in your process map/workflow.
    - If patient is 11-21 years old, additionally give the adolescent screening.
    - Do not make any changes to the tool
- After completion, complete the ‘Study’ and ‘Act’ sections of the PDSA and email to info@improvecarenow.org.
  - How did the process go in comparison to your prediction?
  - What questions came up as they tool was being completed?
    - Were all the questions on the tool answered?
  - Were you successful in sharing the responses with the provider?
  - Was anything in the plan of care changed because of the answers provided?
  - What will you do differently next time?