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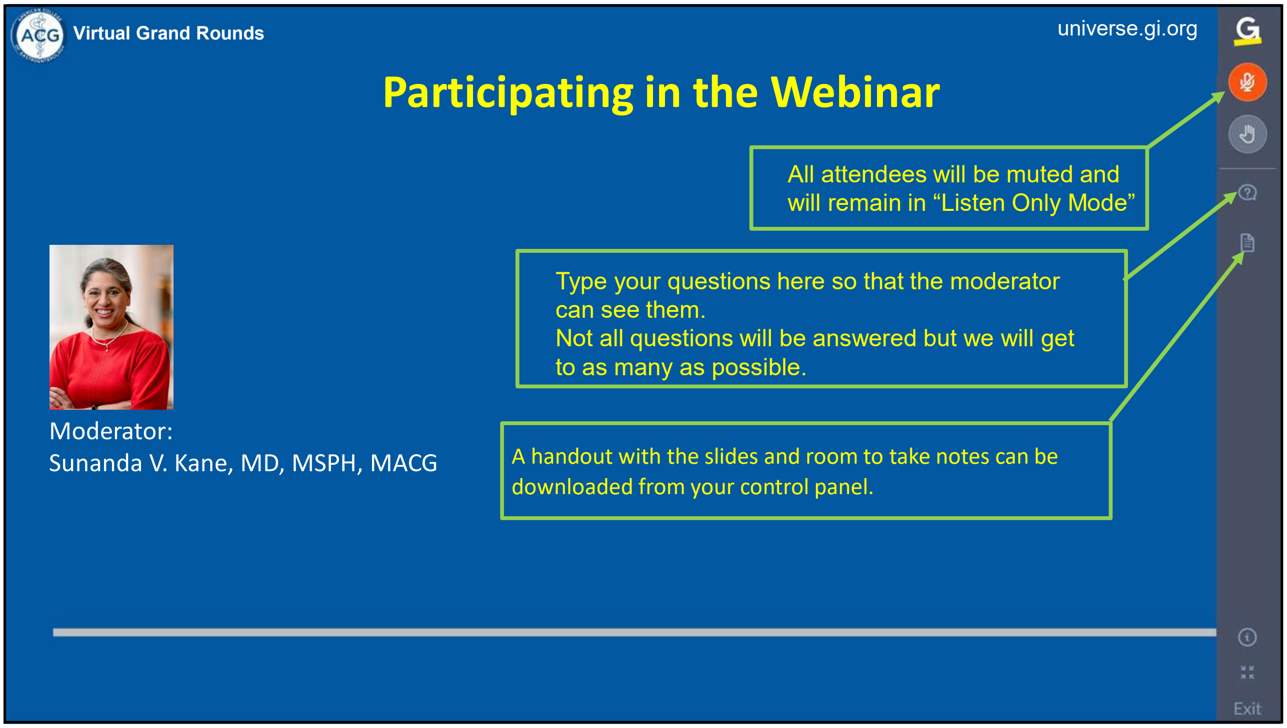

Virtual Grand Rounds

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Participating in the Webinar

All attendees will be muted and will remain in "Listen Only Mode"

Type your questions here so that the moderator can see them.
Not all questions will be answered but we will get to as many as possible.

A handout with the slides and room to take notes can be downloaded from your control panel.

Moderator:
Sunanda V. Kane, MD, MSPH, MACG

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ACG Virtual Grand Rounds

Join us for upcoming Virtual Grand Rounds!

Week 37 – Thursday September 11, 2025
Update in UC and the New ACG Guidelines
Faculty: David T. Rubin, MD, FACG
Moderator: Shannon Chang, MD, FACG
At Noon and 8pm Eastern

Week 38 – Thursday September 18, 2025
Inaugural LIVE ENDOSCOPY Event: Diagnostic and Therapeutic UGI Endoscopy: Back to the Basics
Faculty: Aziz Aadam, MD, Gregory B. Haber, MD, Jasmine Sinha, MD, and Srinadh Komanduri, MD
Moderator: Fernando Fluxa, MD, J. Andy Tau, MD, Mohammad Bilal, MD, and Shivangi T. Kothari, MD, FACG
From 12:00 Noon – 2:30 PM ET

Week 39 – Thursday September 25, 2025
ACG-CGA Joint Webinar- Hereditary Cancer Week- 2025
Faculty: Katherine Germansky, MD, and Pooja Dharwedkar, MD
Moderator: Gautam Naresh Mankaney, MD
At Noon and 8pm Eastern

Visit **gi.org/ACGVGR** to Register

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Disclosures

Ms. Sneha Dave :
No relevant financial relationships with ineligible companies.

Ms. Rosa Kelekian :
No relevant financial relationships with ineligible companies.

Sunanda V. Kane, MD, MSPH, MACG:
Boerhinger Ingelheim: Consultant;Bristol Meyers Squibb: Advisory Committee/Board Member; Fresenius Kabi: Advisory Committee/Board Member; Gilead: Advisory Committee/Board Member; Janssen: Consultant; Lilly: Advisory Committee/Board Member; Pfizer: Advisory Committee/Board Member; Takeda: Advisory Committee/Board Member; UptoDate: Independent Contractor

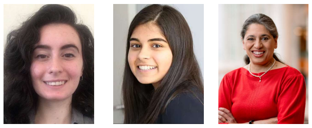
**All of the relevant financial relationships listed for these individuals have been mitigated*

ACG Grand Rounds:
Patients Needs and Satisfaction in the IBD Transition to Adult Care

Rosa Kelekian, MSW: *Programs Manager, Generation Patient/CCYAN*

Sneha Dave, BA: *Executive Director, Generation Patient/CCYAN*

Sunanda Kane, MD, MSPH, MACG: *Chief Patient Experience Officer, Mayo Clinic*



Objective:

Discuss challenges and recommendations related to the transition of IBD patients from pediatric to adult care.

Goals:

- **Better understand some of the unique needs of young adult IBD patients, particularly during transition of care.**
- **Identify 1-2 recommendations to incorporate into practice when working with young adult patients.**
- **Consider opportunities for future research.**

Session Agenda

- Background: The Young Adult Patient
- About the Roundtable on Young Adults with IBD
- Roundtable Findings
- Recommendations: Supporting Young Adults with IBD
- Opportunities for Future Research
- Additional Resources

The Young Adult (YA) Patient

Ages 18-34

- Agency
- Identity
- Self-management
- Self-advocacy
- Self-efficacy
- Burnout

Work

Financial independence

Relationships

Identity

School

Appointments and treatments

The Young Adult (YA) Patient

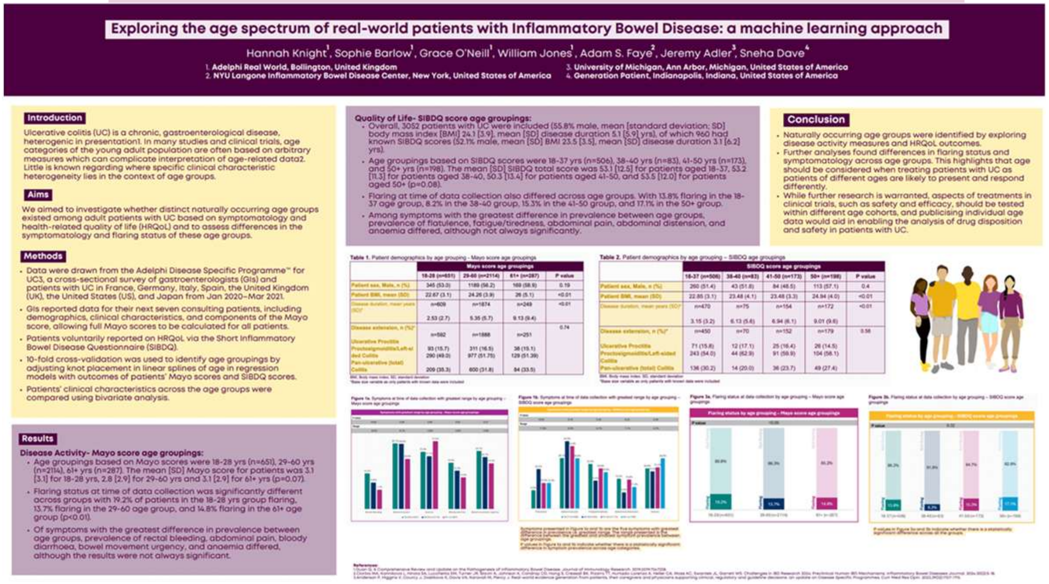
- Young adults with a chronic illness are at an increased risk of developing a psychiatric disorder, leading to an increased risk of having suicidal thoughts (28%), having a death by suicide (134%) and attempting suicide (363%).
- Important to establish interventions for young adult patients with IBD to help them navigate their health with their healthcare team.

Key point: need for peer support, mental health support & patient activation

Source: 1 Mark A. Ferro, Anne E. Rhodes, Melissa Kimber, Laura Duncan, Michael H. Boyle, Katholiki Georgiades, Andrea Gonzalez, Harriet L. MacMillan. Suicidal Behaviour Among Adolescents and Young Adults with Self-Reported Chronic Illness. The Canadian Journal of Psychiatry, 2017; 070674371772724 DOI: 10.1177/0706743717727242

Source: 2 Cho R, Wickert NM, Klassen AF, Tsangaris E, Marshall JK, Brill H. Identifying Needs in Young Adults With Inflammatory Bowel Disease: A Qualitative Study. Gastroenterol Nurs. 2018 Jan/Feb;41(1):19-28. doi: 10.1097/SGA.0000000000000288. PMID: 29373352.

Need for Global Consensus on Young Adults with IBD



Exploring the age spectrum of real-world patients with Inflammatory Bowel Disease: a machine learning approach

Hannah Knight[1], Sophie Barlow[1], Grace O'Neill[1], William Jones[1], Adam S. Faye[2], Jeremy Adler[3], Sneha Dave[4]
1. Adelphi Real World, Bollington, United Kingdom
2. NYU Langone Inflammatory Bowel Disease Center, New York, United States of America
3. University of Michigan, Ann Arbor, Michigan, United States of America
4. Generation Patient, Indianapolis, Indiana, United States of America

Introduction

Ulcerative colitis (UC) is a chronic, gastroenterological disease, heterogenic in presentation1. In many studies and clinical trials, age categories of the young adult population are often based on arbitrary measures which can complicate interpretation of age-related data2. Little is known regarding where specific clinical characteristic heterogeneity lies in the context of age groups.

Aims

We aimed to investigate whether distinct naturally occurring age groups existed among adult patients with UC based on symptomatology and health-related quality of life (HRQoL) and to assess differences in the symptomatology and flaring status of these age groups.

Methods

- Data were drawn from the Adelphi Disease Specific Programme™ for UC3, a cross-sectional survey of gastroenterologists (GIs) and patients with UC in France, Germany, Italy, Spain, the United Kingdom (UK), the United States (US), and Japan from Jan 2020–Mar 2021.
- GIs reported data for their next seven consulting patients, including demographics, clinical characteristics, and components of the Mayo score, allowing full Mayo scores to be calculated for all patients.
- Patients voluntarily reported on HRQoL via the Short Inflammatory Bowel Disease Questionnaire (SIBDQ).
- 10-fold cross-validation was used to identify age groupings by adjusting knot placement in linear splines of age in regression models with outcomes of patients' Mayo scores and SIBDQ scores.
- Patients' clinical characteristics across the age groups were compared using bivariate analysis.

Results

Disease Activity- Mayo score age groupings:

- Age groupings based on Mayo scores were 18-28 yrs (n=651), 29-60 yrs (n=2114), 61+ yrs (n=287). The mean [SD] Mayo score for patients was 3.1 [3.1] for 18-28 yrs, 2.8 [2.9] for 29-60 yrs and 3.1 [2.9] for 61+ yrs (p=0.07).
- Flaring status at time of data collection was significantly different across groups with 19.2% of patients in the 18-28 yrs group flaring, 13.7% flaring in the 29-60 age group, and 14.8% flaring in the 61+ age group (p<0.01).
- Of symptoms with the greatest difference in prevalence between age groups, prevalence of rectal bleeding, abdominal pain, bloody diarrhoea, bowel movement urgency, and anaemia differed, although the results were not always significant.

Quality of Life- SIBDQ score age groupings:

- Overall, 3052 patients with UC were included (55.8% male, mean [standard deviation; SD] body mass index [BMI] 24.1 [3.9], mean [SD] disease duration 5.1 [5.9] yrs), of which 960 had known SIBDQ scores (52.1% male, mean [SD] BMI 23.5 [3.5], mean [SD] disease duration 3.1 [6.2] yrs).
- Age groupings based on SIBDQ scores were 18-37 yrs (n=506), 38-40 yrs (n=83), 41-50 yrs (n=173), and 50+ yrs (n=198). The mean [SD] SIBDQ total score was 53.1 [12.5] for patients aged 18-37, 53.2 [11.3] for patients aged 38-40, 50.3 [13.4] for patients aged 41-50, and 53.5 [12.0] for patients aged 50+ (p=0.08).
- Flaring at time of data collection also differed across age groups. With 13.8% flaring in the 18-37 age group, 8.2% in the 38-40 group, 15.3% in the 41-50 group, and 17.1% in the 50+ group.
- Among symptoms with the greatest difference in prevalence between age groups, prevalence of flatulence, fatigue/tiredness, abdominal pain, abdominal distension, and anaemia differed, although not always significantly.

Conclusion

- Naturally occurring age groups were identified by exploring disease activity measures and HRQoL outcomes.
- Further analyses found differences in flaring status and symptomatology across age groups. This highlights that age should be considered when treating patients with UC as patients of different ages are likely to present and respond differently.
- While further research is warranted, aspects of treatments in clinical trials, such as safety and efficacy, should be tested within different age cohorts, and publicising individual age data would aid in enabling the analysis of drug disposition and safety in patients with UC.

Table 1. Patient demographics by age grouping - Mayo score age groupings

	Mayo score age groupings			
	18-28 (n=651)	29-60 (n=2114)	61+ (n=287)	P value
Patient sex, Male, n (%)	345 (53.0)	1189 (56.2)	169 (58.9)	0.19
Patient BMI, mean (SD)	22.67 (3.1)	24.26 (3.9)	26 (5.1)	<0.01
Disease duration, mean years (SD)*	n=609 2.53 (2.7)	n=1874 5.35 (5.7)	n=249 9.13 (9.4)	<0.01
Disease extension, n (%)*	n=592	n=1888	n=251	0.74
Ulcerative Proctitis	93 (15.7)	311 (16.5)	38 (15.1)	
Proctosigmoiditis/Left-sided Colitis	290 (49.0)	977 (51.75)	129 (51.39)	
Pan-ulcerative (total) Colitis	209 (35.3)	600 (31.8)	84 (33.5)	

BMI, Body mass index; SD, standard deviation
*Base size variable as only patients with known data were included

Table 2. Patient demographics by age grouping – SIBDQ age groupings

	SIBDQ score age groupings				
	18-37 (n=506)	38-40 (n=83)	41-50 (n=173)	50+ (n=198)	P value
Patient sex, Male, n (%)	260 (51.4)	43 (51.8)	84 (48.5)	113 (57.1)	0.4
Patient BMI, mean (SD)	22.85 (3.1)	23.48 (4.1)	23.48 (3.3)	24.94 (4.0)	<0.01
Disease duration, mean years (SD)*	n=470 3.15 (3.2)	n=75 6.13 (5.6)	n=154 6.94 (6.1)	n=172 9.01 (9.6)	<0.01
Disease extension, n (%)*	n=450	n=70	n=152	n=179	0.58
Ulcerative Proctitis	71 (15.8)	12 (17.1)	25 (16.4)	26 (14.5)	
Proctosigmoiditis/Left-sided Colitis	243 (54.0)	44 (62.9)	91 (59.9)	104 (58.1)	
Pan-ulcerative (total) Colitis	136 (30.2)	14 (20.0)	36 (23.7)	49 (27.4)	

BMI, Body mass index; SD, standard deviation
*Base size variable as only patients with known data were included

Figure 1a. Symptoms at time of data collection with greatest range by age grouping – Mayo score age groupings

Figure 1b. Symptoms at time of data collection with greatest range by age grouping – SIBDQ score age groupings

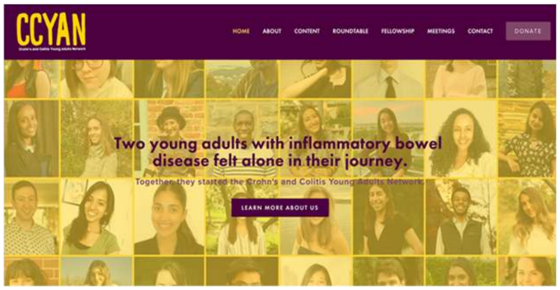
Figure 2a. Flaring status at data collection by age grouping – Mayo score age groupings

Figure 2b. Flaring status at data collection by age grouping – SIBDQ score age groupings

About the Crohn's & Colitis Young Adults Network

universe.gi.org

A program created and led by young adults with IBD: working to drive research, systems change, and direct support.



Two young adults with inflammatory bowel disease felt alone in their journey.

Together, they started the Crohn's and Colitis Young Adults Network.

International Fellowship

Bringing together YA with IBD from around the world and providing opportunities to learn about/engage in IBD advocacy

9	**countries represented in our Fellowship Program**
40	**Alumni from around the world, in fields like medicine, law, advocacy, research, and more!**
400+	**articles and videos created by and for young adults with IBD**

Peer-Support Groups

650+	**peer-support meetings hosted for young adults with IBD and chronic medical conditions**

About the Crohn's & Colitis Young Adults Network

Roundtable on Young Adults with IBD

- A yearlong multidisciplinary discussion series, bringing together patients and providers to discuss eight "domains" of young adulthood where IBD patients often need additional support
- Proceedings published in *Health Care Transitions*
- Developed clinician-facing resources with recommendations for addressing unique needs of YA with IBD

Health Care Transitions

Open access

Special issue

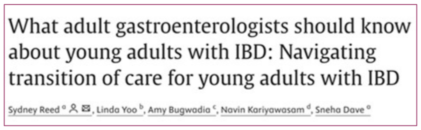
Roundtable on Young Adults with Inflammatory Bowel Diseases

Last update 4 September 2023

Editor's Note: Special Collection of Roundtables on Young Adults with Inflammatory Bowel Disease (IBD) We are very pleased to feature a Special Collection of Roundtables on Young Adults with Inflammatory Bowel Disease (IBD). Each of the Roundtables provide important perspectives of their lived experiences of young adults with IBD by this group of young adults themselves. As readers will find, their views provide new insights that will serve to enlarge understanding of those who are involved with providing care and the recipients of care during this important period of transition to adulthood and transfer to adult health care for not only young adults with IBD but for all adolescents. The readers will find these Roundtables present not only IBD-specific issues but commonalities of concern for all adolescents. This Special Collection exemplifies the mission of Health Care Transitions to advance the science and practice of health care transition that improves health and psychosocial outcomes for all adolescents and young adults.

Peer support interventions for young adults with inflammatory bowel diseases

Sneha Dave [a], Amy Bugwadia [a b], Sara Ahola Kohut [c d e], Sydney Reed [a], Mara Shapiro [a], Hilary K. Michel [f g]

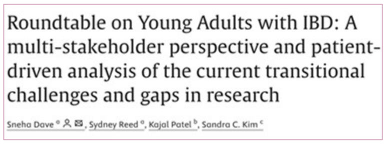


What adult gastroenterologists should know about young adults with IBD: Navigating transition of care for young adults with IBD

Sydney Reed [a], Linda Yoo [b], Amy Bugwadia [c], Navin Kariyawasam [d], Sneha Dave [a]

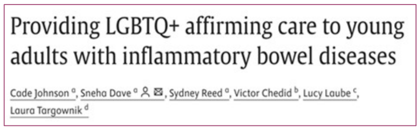
Sexual and reproductive health considerations in the care of young adults with inflammatory bowel disease: A multidisciplinary conversation

Sydney Reed [a], Amy K. Bugwadia [a b], Sneha Dave [a], Hannah E. Wilson [c], Prathikka Ramesh, Hilary K. Michel [e]



Roundtable on Young Adults with IBD: A multi-stakeholder perspective and patient-driven analysis of the current transitional challenges and gaps in research

Sneha Dave [a], Sydney Reed [a], Kajal Patel [b], Sandra C. Kim [c]



Providing LGBTQ+ affirming care to young adults with inflammatory bowel diseases

Cade Johnson [a], Sneha Dave [a], Sydney Reed [a], Victor Chedid [b], Lucy Laube [c], Laura Targownik [d]

Roundtable Findings:

Challenges of Transition & Unique Considerations for Working with Young Adult Patients

- **Inadequate preparation/support in learning self-management skills**
    - “tossed into” the adult care world, pressure to learn too many new skills or information at once can be overwhelming
- **Gaps in care between last pediatric and first adult care visits**
    - Hesitation and barriers (insurance, logistical questions, lack of system integration, etc)
    - delayed check-ups/care, missed medications
- **General lack of psycho-social support throughout the process**
    - fear, anxiety, unsure what to expect, etc.

Systems-level barriers:

- **Lack of time and dedicated staff** to support patients through process
- **Lack of healthcare policies** addressing the needs of transitioning YA with chronic conditions (when to start, what resources exist, who does what, etc.)
- **Absence of systems that effectively share patient data between pediatric and adult care clinics/clinicians**
- Exploring the cost-effectiveness for a medical practice for the role of a **nurse transition coordinator**

What are other barriers or challenges you have seen in your practice?

Virtual Grand Rounds

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Recommendations:

Supporting Young Adults with IBD

Virtual Grand Rounds

*Psychosocial support is key

Ex: Peer support

- Participants expressed social isolation, difficulty connecting with healthy peers, and desire for greater availability of peer support.
- 72 % (n = 96) reported a UCLA loneliness score ≥ 6 (indicating loneliness); 91 % (n = 119) expressed that it was important to them to know other chronically ill young adults.
- 90 % of respondents (n = 122) noted that symptoms or physical limitations from their chronic condition limited them from doing things they wanted to do.
- Only 11 % (n = 15) reported that their hospital provided peer support programming.

Health Care Transitions
Volume 3, 2025, 100114

Peer-support needs and experiences of young adults with chronic conditions: A mixed methods study

Katherine Melton PhD, RN [a], Brynn Telenko [a], Peyton Miles [b], Sneha Dave [b], Sydney Reed [b], Rosa Kelekian MSW [b], Caroline Walsh [b], Shannon O'Donnell [a], Kathleen E. Walsh MD, MS [a]

Introduction

Little is known about how young adults with chronic conditions view peer support and virtual peer-support programming. The purpose of this study is to (1) describe the psychosocial and peer support needs of young adults with different chronic conditions and (2) evaluate the acceptability of a virtual community led peer-support program.

Methods

We developed and pilot-tested a 64-item online survey that included items about demographics, diagnosis and disease severity, peer support use and beliefs, program use and satisfaction, the UCLA 3-item loneliness scale, and free text responses. 136 young adults (18–35) with chronic conditions recruited from an email listserv participated. Two researchers coded free text responses and integrated quantitative and qualitative data using a convergent parallel mixed methods approach.

“Peer support has been something that keeps me going. I need that monthly or bi-weekly check in to be ok with dealing with the hard stuff. Even if we are not discussing our medical stuff just being around others that I don't need to explain or apologize if I’m unwell or can't answer a question (#12, inflammatory bowel disease, other comorbidities).”

Melton et al (2025); https://www.sciencedirect.com/science/article/pii/S2949923225000200

- **Normalize the variety of feelings** (e.g., nervousness, hesitation) that YA may experience when learning new skills or gaining independence
- Emphasize that transition of care does not entail or necessitate complete "independence" – **encourage patients to ask for help when they need it**
- **Help YA identify who on their medical team they can/should go to with different questions**

"It is normal to feel excited, nervous, or both when we're thinking about getting older and gaining independence! How are you feeling? How can I support you?"

"Just because you're growing older or taking on more responsibilities doesn't mean you have to do it all alone! An important part of the transition process is learning how, when, and who to ask for support."

- Focus less on what patients "should" be able to do by a certain age -- **meet them where they are** and **celebrate 'small wins'**
- Focus on ***one goal at a time***
- Identify **incremental steps** for skill building
- **Ask, don't assume**: Instead of "do you have any questions?" use open-ended questions/prompts

"What are some concerns you have about transitioning to adult care?"

"What are some things that excite/intrigue you?"

"What are some questions you have about ______?"

- Encourage patients to **build self-advocacy skills**, and **validate** that they are an expert in their own body/life
- **Listen, validate, share, and ask.**
    - Instead of “I don’t think X symptom is anything to worry about”
- YA patients are often still learning how and what information they should share with providers, so may need some prompting

Listen/Validate: *“It sounds like X symptom is [impacting Y, concerning you, etc.].”*

Share: *“These are some possible reasons why you might be experiencing X, and this is how we might rule out other possibilities.”*

Ask: *“What do you think about what I shared?”*

“Can you share more about how X symptom is impacting you/your daily functioning? That will help me figure out if it’s something we should keep an eye on, or if we should order XYZ tests today.”

“Thanks for bringing that to my attention – that’s a good thing to keep an eye on! It sounds like right now, it’s not causing you major issues, but if you start noticing XYZ, definitely let me know.”

Opportunities and Ongoing Needs for Future Research

- Assess **long-term impact** of transition programs (on health outcomes, quality of life, and healthcare utilization) → show need for funding
- Understand **barriers/facilitators for implementing** effective transition programs in different settings → showing how to have most impact
- **Consensus on core outcome measures** for evaluating transition programs → better comparison across studies/programs
- More **multidisciplinary collaboration** between gastroenterology, mental health, nursing, social work, public health researchers, etc. → address the multifaceted nature of transition

- **Collaboratively** design, implement, and evaluate interventions **alongside YA patients:** Community-based participatory research, Community-engaged research, Patient Advisory Boards

Check out our CCYAN Directory: a resource to connect researchers with YA IBD patients (for advisory boards, research teams, etc.)

CCYAN | Crohn's & Colitis Young Adults Network

IBD Patient Engagement: CCYAN Directory

Learn more about our work at www.ccyannetwork.org!

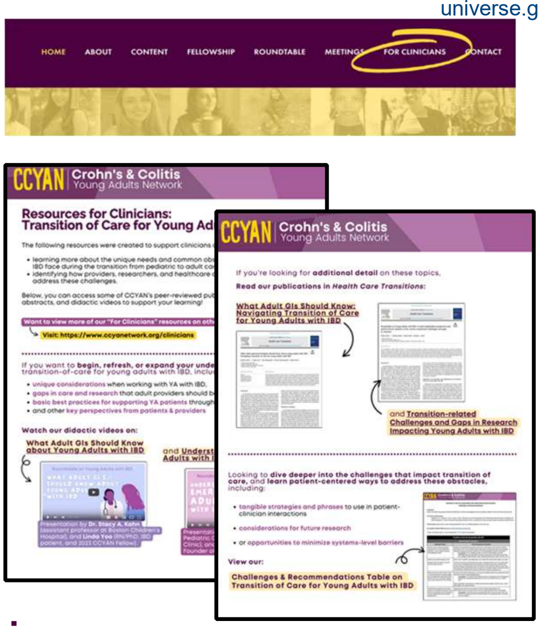
- **Qualitative** or **mixed-methods** studies to more fully understand lived experiences/preferences of YA patients

- **Peds/adult collaboration** to gather data/understand ongoing patient needs and satisfaction

What are other research gaps/needs you see in your practice?

'For Clinicians' Resources

- Transition of Care
- Sexual and Reproductive Health
- Providing LGBTQ+ Affirming Care
- Caring for YA Men with IBD
- Medical Trauma
- Peer Support Interventions
- Higher Education and the Workplace
- Clinical Trials



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Resources for Clinicians:
Transition of Care for Young Ad

The following resources were created to support clinicians

- learning more about the unique needs and common ob IBD face during the transition from pediatric to adult ca
- identifying how providers, researchers, and healthcare address these challenges.

Below, you can access some of CCYAN's peer-reviewed pu abstracts, and didactic videos to support your learning!

Want to view more of our "For Clinicians" resources on oth

Visit: https://www.ccyanetwork.org/clinicians

If you want to begin, refresh, or expand your unde transition-of-care for young adults with IBD, inclu

- unique considerations when working with YA with IBD,
- gaps in care and research that adult providers should b
- basic best practices for supporting YA patients through
- and other key perspectives from patients & providers

Watch our didactic videos on:

What Adult GIs Should Know about Young Adults with IBD

and Underst Adults with I

Presentation by Dr. Stacy A. Kahn (assistant professor at Boston Children's Hospital), and Linda Yoo (RN/PhD, IBD patient, and 2023 CCYAN Fellow)

CCYAN | Crohn's & Colitis Young Adults Network

If you're looking for additional detail on these topics,

Read our publications in *Health Care Transitions*:

What Adult GIs Should Know: Navigating Transition of Care for Young Adults with IBD

and Transition-related Challenges and Gaps in Research Impacting Young Adults with IBD

Looking to dive deeper into the challenges that impact transition of care, and learn patient-centered ways to address these obstacles, including:

- tangible strategies and phrases to use in patient-clinician interactions
- considerations for future research
- or opportunities to minimize systems-level barriers

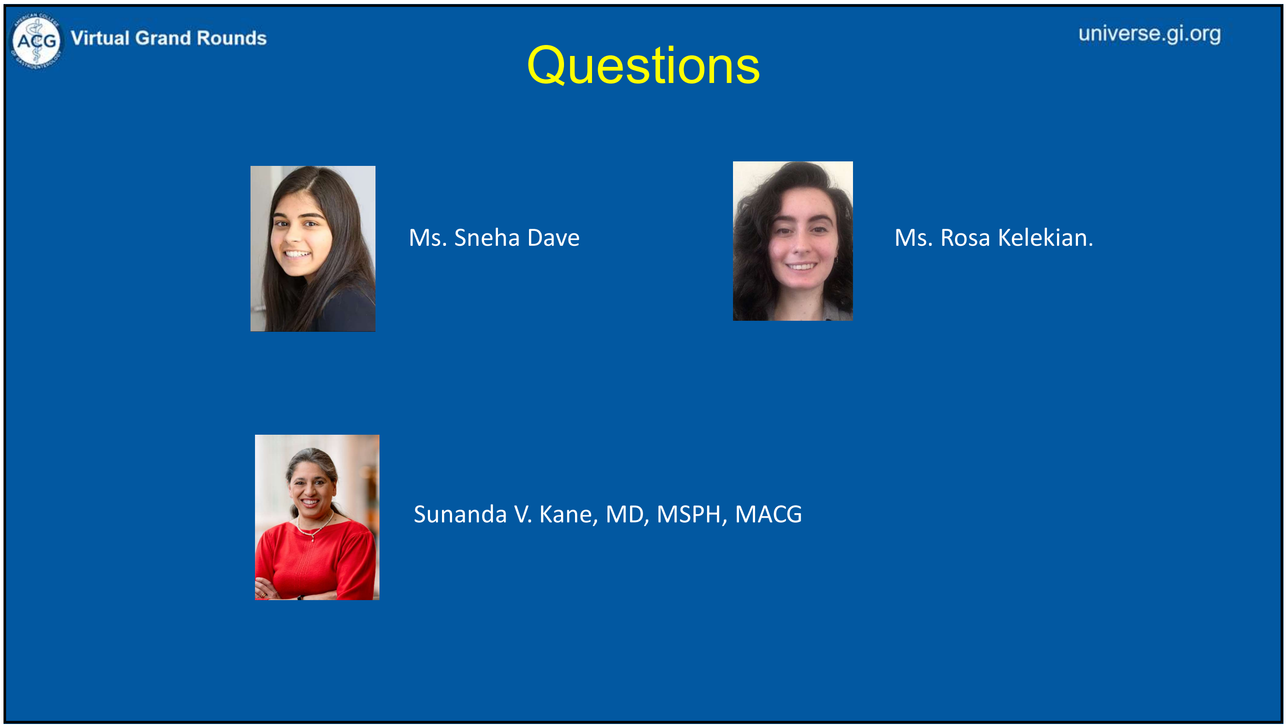
View our:

Challenges & Recommendations Table on Transition of Care for Young Adults with IBD

https://www.ccyanetwork.org/clinicians

Sign up for our CCYAN newsletter here!

For more information, please visit **ccyanetwork.org,** follow us on social media **@ccyanetwork,** or email us at admin@generationpatient.org.



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Questions

Ms. Sneha Dave

Ms. Rosa Kelekian.

Sunanda V. Kane, MD, MSPH, MACG

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IBD Circle
A Partnership of the American College of Gastroenterology and the Crohn's & Colitis Foundation