Center for Health Care Strategies

Dedicated to strengthening the U.S. health care system to ensure better, more equitable outcomes, particularly for people served by Medicaid.

Together with our partners, our work advances:

- **Effective models for prevention and care delivery** that harness the field’s best thinking and practices to meet critical needs.

- **Efficient solutions for policies and programs** that extend the finite resources available to improve the delivery of vital services and ensure that payment is tied to value.

- **Equitable outcomes for people** that improve the overall wellbeing of populations facing the greatest needs and health disparities.
Agenda

• Welcome and Introductions
• Youth Leadership Spotlight
• Incorporating Youth Perspectives in Primary Care
• Moderated Q&A
Questions?

To submit a question online, please click the Q&A icon located at the bottom of the screen.
Today’s Presenters & Panelists

Hannah Gears, MSW,
Senior Program Officer,
Center for Health Care Strategies

Sneha Dave,
Founder and Executive Director,
Generation Patient

Heidi Shreck, MD,
Pediatrician and Chief Medical Officer,
Primary Health Care Iowa

Elena Gentry,
Primary Health Care Iowa,
Youth Advisory Board Representative

Kathleen Loder,
Primary Health Care Iowa,
Youth Advisory Board Representative
The Need for Accelerating Child Health Transformation
Strategies & Levers to Accelerate Child Health Transformation

- Adopt **anti-racist practices and policies** to advance health equity
- Co-create **equitable partnerships** with patients, families, and providers
- Identify **family strengths** and address **health-related social needs**

Implement **payment and accountability levers** to support and sustain transformation
Foundational Steps for Transformation

Putting patients and families at the center of decision-making is foundational for providers looking to transform culture, policies, and practices. This may look like:

- **Engage patients and families** meaningfully throughout the transformation process so they can inform improvements and understand how their contributions are used.
- **Value patients’ and families’ time** by compensating them for time spent providing feedback and sharing their expertise.
- **Support patients’ and families’ ability to engage** by providing necessary resources, training, and flexibility.
- **Disrupt existing power dynamics** by enabling patients and families to co-lead transformation work.
- **Listen to youth voices** by developing opportunities to hear from child and adolescent patients directly.
Youth Leadership Spotlight

Sneha Dave, Founder and Executive Director, Generation Patient
At age 13, I had my colectomy surgery after living with recurrent flares since the age of six. This is a picture of me right after my first of three major surgeries.

That same year, with my late best friend, I created the Crohn's and Colitis Teen Times to connect young adults with IBD in Indiana. This is the front cover of our first newsletter in 2013.
Events

HAS
HEALTH ADVOCACY SUMMIT

The Health Advocacy Summit is the prior name of the overall organization but now serves as the name for our virtual and in-person events. Prior to the pandemic, we facilitated seven in-person Summits in four states and during the pandemic, we have facilitated three international virtual Summits.

Programs

CCYAN
Crohn’s and Colitis Young Adults Network

The Crohn’s and Colitis Young Adults Network (CCYAN) facilitates a fellowship program, community space, and more for young adults with Inflammatory Bowel Diseases. CCYAN is the only disease-specific programming of Generation Patient.

(HEALTH) policy lab

The mission of the (Health) Policy Lab is to provide health policy education and advocacy opportunities to young adults with chronic and rare conditions in an effort to increase meaningful access to prescription medications.

& More!

- 7 Virtual Meetings per month
- Roundtables to bring together stakeholders on a variety of topics
- Advocacy to increase access to higher education
- Critical resources for our community, including civic engagement and advance care planning.
Disclosures

We have no disclosure to report.

Our support comes from foundations such as the Helmsley Charitable Trust, Arnold Ventures, the Disability Inclusion Fund, the Commonwealth Fund, the Third Wave Fund, and the Lumina Foundation.

We are independent of all industry funding.
<table>
<thead>
<tr>
<th>Year</th>
<th>Topics</th>
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</table>
| 2020 | - Global Health Policy: Drug Pricing  
- ADA & Accommodations: Self-Advocacy tips for Transitioning From Pediatric to Adult Care  
- International Perspectives: Chronic Illness in India  
- Mental Health: Emotional Dimensions of Chronic Illness  
- Navigating Insurance in the U.S.  
- Intersecting Identities & Minority Health  
- Mindfulness & Movement  
- Navigating Higher Education  
- Telling Your Story: Communicating With Peers, Loved Ones, & Medical Professionals  
- Chronic Illness & Entrepreneurship |
| 2021 | - Global Health Policy: Pharmaceutical Patents  
- Advocating for Your Future: Higher Education and the Workplace  
- Adaptive Ballet Class  
- Digital Activism: Grassroots Patient Advocacy  
- Intersecting Identities  
- Financial Resources  
- Emotional Wellbeing  
- International Perspectives: Malaysia, Uganda, and India  
- Exploring Art Therapy: An Interactive Session  
- Media Representation of Chronic Illness  
- Confidence & Body Image |
| 2022 | - Dysautonomia & Chronic Illness  
- Art Workshop: A Therapeutic, Interactive Session  
- Medical Trauma and Growth  
- A Conversation With Grassroots Activists  
- Decolonizing Patient Advocacy  
- Diagnosed: Grief, Identity, Acceptance, & the Unknown  
- Neurodivergence & Chronic Conditions  
- Global Access to Medicines  
- Higher Education, the Workplace, & Self-employment  
- Movement & Mindfulness  
- A Conversation with Selma Blair and Troy Nankin |
Peer Support Meetings

Since March 2020, we have held over 450 virtual meetings to connect young adult patients on a national and international scale. **We currently host at least six virtual community meetings each month.**

We currently offer the following virtual support meetings for our community:

- General Support Meetings for Young Adult Patients
- Virtual Community Sessions for Young Adults with IBD
- Higher Education Student Support Network
- Virtual Meetings for Siblings of Young Adult Patients
Nineteen percent of undergraduates in 2015–16 reported having a disability.

How many disabilities are underreported, particularly chronic medical disabilities?

Our Roundtable on Chronic Medical Disabilities and Higher Education highlighted the most pressing needs for students who are entering these institutions. We published Proceedings from this Roundtable.
SAT & ACT Experiences Survey for Students with Chronic Medical Conditions

This survey assesses the experiences of students with chronic medical conditions (including chronic illnesses and rare diseases) who have taken the ACT or SAT. This survey was designed by Generation Patient (formerly known as the Health Advocacy Summit). For any questions, please contact Amy Bugwadia, Generation Patient’s Higher Education Coordinator at amy@healthadvocacysummit.org.

This questionnaire is focusing on chronic medical conditions (such as chronic illnesses and rare diseases) specifically. For the purposes of this survey, the term “chronic condition” (sometimes referred to as a “chronic medical disability” or “chronic health condition”) refers to chronic illnesses and rare diseases, including (but not limited to) Crohn’s disease, rheumatoid arthritis, diabetes, POTS, and lupus. You do not have to have a formal diagnosis to complete this survey.

We are aware that other disabilities (such as learning disabilities) can and do affect students’ preparation and performance on standardized tests. For the purposes of this survey, we are hoping to specifically capture the impact of your chronic medical condition on your standardized testing experiences. However, we do understand that different disabilities can be difficult to separate and differentiate between.

This survey will take about 10 minutes to complete and will be used by Generation Patient to advocate for increased access and equity in higher education for students with chronic conditions. All personally-identifiable information will be kept private, and survey results will be shared in aggregate form (rather than on an individual level).

Our survey on the SAT and ACT Experiences Survey for Students with Chronic Medical Conditions is directed toward College Board and the ACT, because we know anecdotally, the difficulty in accessing accommodations. We are doing this in conjunction with Dr. Ann Shih at Virginia Commonwealth University.
WHO WE ARE

The CCYAN is a community and international fellowship program for young adults with IBD.

OUR FELLOWSHIP

We facilitate a yearlong fellowship that brings together a select group of young adults with IBD from around the world. Our fellows produce monthly content, convene virtually to hear from influential speakers, engage in speaking opportunities and receive a stipend for their participation.

AND MORE...

- Virtual community meetings for young adults with IBD
- Roundtable on Young Adults with IBD - a yearlong learning community comprised of monthly discussions between patients and providers
- IBD Medical Student Scholars - a unique program for medical students interested in gastroenterology and internal medicine to learn about the global challenges and needs of adolescents and young adults with IBD

270

The number of articles or videos created by and for young adults with IBD since 2020.

4

Countries represented in our 2022 Fellowship Program.
In 1992, Christine Hayes of the Huntington’s Disease Society of America said ‘hope is no good if a drug is developed and our folks cannot afford it’.

The (Health) Policy Lab is a program through Generation Patient established in January 2022, to provide health policy education and advocacy opportunities to young adults with chronic conditions.
According to the Georgetown University McCourt School of Public Policy, 53% of people ages 18-34 use prescription drugs.

Moreover, **21% of people ages 18-49 years old** say they have difficulty affording their medication (Kaiser Family Foundation, 2019).

The share is likely to be even higher for younger adults as the highest poverty rate in the United States is between the ages of 18-24 (Statista, 2022).
Patent Reform and our work with the USPTO/FDA Collaboration

- Between 1995 and 2015, 60 pharmaceutical companies merged into 10.
- Between 2005 and 2015, 78 percent of drug patents were related to drugs already on the market.
- Over 100 patents granted to Humira *after* FDA Approval.
Health Policy Scholars Program

This program is for young adult patients interested in health policy education, who will meet monthly to discuss critical issues in the health policy and economic landscape and engage in opportunities to get involved in key policy areas.

Combining peer support, education, and opportunity.
Health Policy Forums

Our forums are independent education opportunities for young adult patients to get involved in issues affecting them.

- **Basics of Prescription Drug Pricing**
  - Gerald Posner, Author of PhRMA
  - Andrew York, Executive Director of Maryland PDAB
  - Hemi Tewarson, Executive Director of NASHP
  - Audrey Baker, Patients For Affordable Drugs

- **PDAB General Informational Meeting**
  - Pranav Pinapala, Generation Patient team

- **Basics of Health Economics**
  - Dr. Hussain Lalani, Brigham and Women's Hospital
  - Dr. Benjamin Rome, Brigham and Women's Hospital
  - Yvette Venable, Institute for Clinical and Economic Review
Clinical Trials and Adverse Event Reporting

- FDA Adverse Event Reporting System
  - 18 and 64-year-olds are grouped together.
  - What would a more reasonable age stratification look like?

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<td>234,621</td>
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Pharmaceutical Direct-to-Consumer Advertising on TikTok and Instagram
The Urgency

9 out of 10 patients ask their doctor about a product after seeing influencer-shared information. (1)
Who is the most vulnerable?

Vulnerable populations, including **adolescents** and individuals with **chronic or hard-to-treat conditions** or those with depression, may be particularly impacted by targeted promotional communications on social media platforms.

(1) Duke Margolis Center for Health Policy
Celebrities

Living life how it should be lived with the help of Nurtec® ODT (rimegepant) 75 mg. Go to @nurtecodt for more info.

Individual results may vary. Nurtec ODT is for the acute treatment of migraine and the preventive treatment of episodic migraine in adults. Prescription only. Don’t take if allergic to Nurtec ODT. The most common side effects were nausea, stomach pain, and indigestion. Talk to your doctor about Nurtec ODT. Swipe for Important Safety Information and see @nurtecodt_pl.

@nurtecodt NurtecODT migrainesuck

4,376 likes
SEPTEMBER 17, 2021
Our Recommendations for Social Media Companies

- A form of social media “flagging”
  - similar to the “sensitive content” warnings seen across various social platforms, we recommend a flag stating:
  - “this content includes information about prescription medications”

[Images of Instagram and TikTok warning interfaces]
Takeaways

- Peer support can be a catalyst for disease acceptance and management.
- Engagement starts with authenticity and transparency.
- Movement building and engagement must be intersectional.
- Reimagine how young people should be involved in technical and policy processes.
- Integrate young people in the processes that exist within your organization/company, there is not always a need to create a separate organizational body dedicated to youth.

Contact Information

Sneha Dave
sneha@generationpatient.org
@genpatient on Instagram
@generationpatient on Twitter
Incorporating Youth Perspectives in Primary Care

Heidi Shreck, MD, Pediatrician and Chief Medical Officer, Primary Health Care Iowa and Youth Advisory Board Representatives, Elena Gentry and Kathleen Loder
PHC School Based Health Clinics
Student Advisory Council
PHC Student Advisory Council
Agenda - February 23, 2023

➔ PHC & DMPS Overview
➔ Why a Youth Council?
➔ Planning, Pre-work & Recruitment
➔ Meet Our Students
➔ Student Reflections
➔ Project Selection & Implementation
➔ Wins, Challenges & Takeaways
Primary Health Care (PHC) is a federally qualified health center or community health center

- Located in central Iowa, urban and rural areas
- **154,661** patient visits in 2022 (calendar year)
- **40,427** total patients
- Provides medical, dental, behavioral health and enabling services (social determinants of health), 340B pharmacy
- Has 9 sites in Polk, Story and Marshall counties
- **30%** number of PHC patients are 0 to 19 years of age
Des Moines Public Schools

- Located in Polk County
- Serving 30,000+ students annually
- Includes 38 elementary, 11 junior high and 5 high schools in addition to 10 alternative/special programming options
- 23% English language learners
- Almost 100 different languages and dialects
- 76% free and reduced lunch
PHC’s school based health clinic history

2016  Opened our first site @ DMPS alternative high school, Scavo

2017  Second clinic opened at Hoover High School

2020  Clinic closed due to all remote and then hybrid learning at DMPS

2020  Scavo (the school itself) closes

2021  Returned to Hoover High School at the start of the school year

2021  Provided SBHC services in mobile unit at auxiliary site, permanent clinic opened at site February 2022

2022  First Student Advisory Council meeting held October 12
Why did we want to form a youth council?

**Visibility**

PHC has two clinics, one located in a high school, the other located at a school community building.

Challenge to get the word out to students, teachers, parents.

Students share own experience & determine what information is shared with their peers as well as how it is delivered.

**Inform care & services**

Allows for a greater pulse on the health needs important to today’s teens.

Students have the most relevant ideas on how to improve services at the clinics.
Patient demographics from 2021-2022 school year

**Ethnicity of Patients seen at School Based Clinics during FY2022**

- Hispanic or Latino: 45%
- Not Hispanic or Latino: 51%
- Other or Undetermined: 3%
- Patient Declined: 1%

**Race of Patients seen at School Based Clinics during FY2022**

- American Indian/Alaskan Native: 6%
- Asian: 7%
- Black or African American: 10%
- More than One Race: 1%
- Native Hawaiian or Other Pacific Islander: 43%
- Patient Declined: 1%
- Unreported: 6%
- White/Caucasian: 30%
nothing about us
without us
— Michael Masutha & William Rowland
Planning & pre-work

- Developed materials such as student application, scope of work, parent letter, available in English and Spanish.
- Sought TA assistance from Nikki Montgomery, family advisor. She reviewed our materials and recommended the use of more plain language. Sid Srivastava (a former youth advisory council member) gave us advice on our recruitment process as well.
- Listed possible school contacts & others who might have ideas, recommendations in our recruitment efforts.
- Selected our patient engagement self assessment survey tool, from the Institute for Patient and Family-Centered Care.
Recruitment

**materials**
- Scope of work
- Parent letter
- Outline of expectations
- Application
- Available in Eng & Span

**outreach**
- Back to school events @ Des Moines high schools
- Posted flyers, QR code with more information
- Community events

**leverage school contacts**
- Community school coordinators
- Guidance counselors
Moises & Madi at a neighborhood event, shared info about PHC services as well as an opportunity for student recruitment.
Students Interviewed & confirmed members in September

<table>
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<tr>
<th>Name</th>
<th>School</th>
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<tbody>
<tr>
<td>Curtis Badio</td>
<td>Roosevelt High School &amp; Central Academy</td>
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<td>Joselyn Chavarria</td>
<td>North High School &amp; Central Academy</td>
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<td>Ellie Gonzalez</td>
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</tr>
<tr>
<td>Maazza Qiraqandi</td>
<td>Roosevelt High School &amp; Central Academy</td>
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</table>
student reflection:  
why did you want to join the student advisory council?

I joined the PHC student advisory council because I have genuine care for our community and I wanted to take part in bettering the experience of students in our schools. I have encountered so many situations where my peers weren't able to access the healthcare that they needed because of insurance, language barriers, or just lack of resources and I knew that these challenges were something that no student should be facing.

PHC SAC has allowed me and the other council members to partake in making that change. The experience I have had being in this council has been full of teamwork, positivity, and amazing thinking. My ideas have been shared and my voice has been heard during my time as a council member.

-Joselyn Chavarria,  
student advisory council founding member, 2022 - 2023

Hi, I’m Ellie Gonzalez, being a part of the PHC student council so far has been amazing. Not only does the project function well with our expertise like myself share our perspective and input for this project. I think of being in this student council as an opportunity and an advantage to be doing something for the Des Moines community.

-Ellie Gonzalez,  
student advisory council founding member, 2022 - 2023
Kickoff meeting

➔ Partnered with CYC to help us with facilitating our first meeting, October 12, 2022.

➔ CYC had fun, creative team building activities.

➔ Developed a “Ground Rules for Engagement” document, with student led ideas & participation.

➔ Settled on day of week & time for future meetings. Sundays, once a month from 4:30 to 6:30

➔ Talked through student compensation & shared an anonymous survey to solicit all opinions. Based on the group’s responses & current wages in the community, $16.50 an hour was the consensus. Students can earn silver cord hours in lieu of compensation.

➔ Served dinner at this & every meeting to follow.

Community Youth Concepts’ mission is to engage and connect Iowa students through youth development programming and to provide coaching, training, and technical assistance in best practices to youth-serving non-profits.

Meals Served
- Pizza, veggie & gluten free (student’s liked it)
- Jimmy John’s (a hit)
- Fried chicken/potato salad & coleslaw (nope)
- Olive Garden (thumbs up)
Ground Rules of Engagement

also described as “how we will show up”
Meeting #2

CYC joined us at our second meeting as well, to assist with facilitating group discussion & brainstorming project ideas for the council.

This meeting included a tour of one of our school based health clinics, students were engaged & asked a lot of great questions.
Project selection & action steps

➔ Narrowed down project ideas, using hot dot, impact/effort diagram

➔ Selected “Increasing Teacher Awareness of SBHC”

➔ Determined steps to take, assigned tasks, and planned a work session on MLK Day (no school). Team met in a conference room at PHC

➔ Shared work via Google folders, planned action for the next few weeks
Flyers created by the Council, include a QR code directed to a landing page with more information. Students researched top five most spoken languages in DMPS high schools and translated into each. *Pictured above are (L to R): Swahili, Spanish, Karen. Not pictured, Burmese and Somali.*
Where we found success

➔ Partnering with CYC team building was key, an organization whose focus is engaging adolescents was helpful
➔ A diverse, enthusiastic, actively engaged group of students
➔ Recruiting juniors & sophomores, hoping some will return to the board having this year of experience
➔ Students shared they feel welcome at meetings & at school based health clinics
➔ Student passion for the project (getting the word out about SBHC)
➔ Using Google drive as a shared workspace, capture ideas & as materials were developed, accessible to all
➔ Students requested very specific action items at end of meetings
Challenges

- Recruiting for gender diversity
- Student representation from all DM high schools
- Time! More time at meetings to accomplish goals & time for staff to support the needs of the council
- Communication in between meetings, students weren’t as responsive as we hoped, on text or email; they are busy!
- Getting more specific feedback from students (tried 1:1 Google Meets which proved difficult to schedule, surveys)

What would we do differently next time?

- Ask for pronoun preferences at the first meeting
- Cultivate stronger relationships within the schools, consider meeting in person
- Enlist the help of others in our org to introduce contacts they may have in schools, assist with recruitment
- Select a shorter survey
Thank you to the CHCS team & our learning collaborative colleagues!

Dr. Heidi Shreck
Chief Medical Officer

Moises Castellanos
Marketing & Community Outreach Specialist

Marissa Conrad
Director of Marketing & Communications

Student Presenters
Kathleen Loder (L)
Elena Gentry (R)
Moderated Q&A
Questions?

To submit a question online, please click the Q&A icon located at the bottom of the screen.
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• Learn about cutting-edge efforts from peers across the nation to enhance policy, financing, and care delivery.

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