



13TH ANNUAL

**Health Care Transition
Research Consortium (HCTRC)**

RESEARCH SYMPOSIUM
VIRTUAL CONFERENCE

October 27, 2021
8 a.m. – 4:15 p.m. CDT

Co-provided by:



13th Annual Health Care Transition Research Consortium Research Symposium
October 27, 2021
Agenda

8:00 AM Opening Remarks

Cecily L. Betz, PhD, RN, FAAN; Megumi J. Okumura, MD, MAS
HCTRRC Research Symposium Co-Chairs

Albert C. Hergneroder, MD
Baylor College of Medicine, Texas Children's Hospital

8:15 AM Platform Session 1: Health Care Transition: International

Transitional Care in Rheumatology: Current Practice in Switzerland
Berben Lut, PhD, RN; Sigg Nor, MD; Daly Mary Louise MSc, RN; Bachmann Stefan MD; Baer Walter MD; Berthet Gérald MD; Bolt Isabel MD; Dan Diana MD; Enderlin Steiger Susanna MD; Fröhlich Johannes MD; Hasler Paul MD; Hofer Michaël, MD; Huemer Christian MD; Kaiser Daniela MD; Marcoli Natalie MD; Palmer Sarott Seraina MD; Rottländer Yella MD; Schmid Gernot MD; Soennichsen Christa RN; Strahm Furler Laura MScN, RN; Vanoni Federica MD; Wildi Lukas MD; Daikeler Thomas MD; Woerner Andreas MD

Healthcare Transition Preparation in Adolescents with Kidney Transplantation or Pretransplant in Cali Colombia

Jaime Restrepo MD; Maria Alejandra Agredo MD; Lina María Viafara MD; María Santa Santamaría; Angela Mantilla; María González; Adriana Palacio; Jhovana Trejos; Hernando Londoño MD; María Ferris MD PhD; Mara Medeiros MD PhD

Healthcare Transition Readiness Self-report Tool: Translation, Cultural Adaptation, and Linguistic Validation of the STARX Questionnaire – Russian Version

Elena Kulakova, MD, PhD, NN; Tatjana Nastausheva, MD, PhD; Oleh Akchurin, MD; Maria Koltakova, MD, NN; Tatjana Zvyagina, MD, PhD, NN; Anastasija Ledovskih, MD, NN; Maria Diaz-Gonzalez de Ferris, MD, MPH, PhD

Using Storytelling to Amplify Voices of Those Who Transitioned Through Healthcare (Scotland)
Sharon Levy MPhil RN; Iona Campbell, BS

Transition Navigator Trial: Evaluating the Impact of a Patient Navigator on Health Care Utilization by Youth with Chronic Disease Transitioning to Adult Care (Canada)

Susan Samuel, MD, MSc; Gina Dimitropoulos, PhD, RSW; Andrew Mackie, MD, MSc; Alberto Nettel-Aguirre, PhD; Daniele Pacaud, MD; Greg Guilcher, MD; Jorge Pinzon, MD; Eddy Lang, MD; Gail Andrew, MD; Lonnie Zwaigenbaum; Shannon Scott, RN PhD; Scott Klarenbach, MD, MSc; Lorraine Hamiwka, MD; Brooke Allemang, MSW, PhD (candidate); Kristin Tinge, BSW; Ken Pfister, MSc; Daniella San Martin Feeney, MSc

9:30 AM Break

9:45 AM Platform Session 2: Continuous Quality Improvement/Program Development Models of Care/Other

Comprehensive Transition Program at a Free-Standing Pediatric Hospital: Demonstrating Impact Utilizing the Current Assessment of Healthcare Transition Activities

Susan Shanske, MSW, LICSW; Suzanne Dahlberg, PhD; Leanne Langmaid, MSN, RN; Jamara Polzin, MSW; Colleen Huysman, MSW, LICSW; Julia Roboff, MSN, FNP-BC, CPN; Nadia Abdulrazak, MSN, ANP-C; Rebecca Berger, FNP; Samantha Covelle, MSN FNP-BC; Cassandra Fleurentin, FNP-BC; Nancy DiTullio, FNP; Kitty O'Hare, MD; Niraj Sharma, MD, MPH; Leah Ratner, MD, MS; Ahmet Uluer, DO, MPH

Health Care Transition in State Public Health Programs: A Review of Current State Title V Block Grant Reports
Samhita Ilango, MSPH; Peggy McManus, MHS; Dan Beck, MA; Patience White, MD, MA

The Use of the "Transition Map" in Care Coordination for the Transitional Patient
Samantha Covelle FNP, BC; Colleen Huysman LICSW; Leanne Langmaid RN MSN

Bridging the Transition Gap; Developing a Transition Program Using QI Methodology

Unoma Akamagwuna, MD, Jensine' Norman, MD

Massachusetts Initiative to Improve Transition to Adult Healthcare for Individuals with Neurodevelopmental Disabilities (NDD): Phase 2
Susan Shanske, LICSW; Sarah Spence, MD, PhD; Jamara Polzin, MSW; Lindsay Hunt, MEd

11:15 AM Break

11:30 AM Poster Session 1

Participants will have access to view posters beginning early October with website links available upon registration. During Session 1, topical breakout sessions will be available to query panels of poster presenters about their work.

12:30 PM Lunch/Breakout Sessions

Engaging Refugee Youth living with HIV into Care – A Community-Based Approach
Neerav Desai MD; Aima Ahonkhai MD, MPH; Leslie Pierce MPH; DeWayne Parker BSW

Intersectionality; An Added Complexity for Health Care Transition
Rita Nathawad, MD; Chanda Jones, MSW(c); Lindsey Hollingsworth, PA-C; Jasmine Brown, MS; Solanica James, LPN; Rashell Lewis, LPN

Special Interest Groups (TBA)

1:15 PM Platform Session 3: Readiness/Self-Management/Education

Health Care Transition Services for Young Adults: Validation of Its Use in the National Survey of Children's Health
Nancy Cheak-Zamora PhD; Chelsea Deroche, PhD; Mojgan Golzy, PhD; Trevor Mandy, BS

Psychometric Properties of the Transition Readiness Assessment Questionnaire (TRAQ) in a Youth Mental Health Sample
Kristin Cleverly, RN, PhD, CPMHN; Sarah Brennenstuhl PhD; Julia Davies RN MN, PhD(c); Brooke Allemang MSW, RSW, PhD(c)

A Transition Curriculum That Enhances Rheumatology Fellows' Ability to Integrate Young Adult Patients into Adult Rheumatology Care
Rebecca Sadun, MD, PhD; Gary R Maslow, MD, MPH; Richard J Chung, MD; Lisa G Criscione-Schreiber, MD, MEd

Sickle Cell Transition Skills Lab: Preliminary Evaluation
Jerlym Porter, PhD, MPH; Sheila Anderson, BSN; Kathryn Russell, PhD; Jennifer Longoria, PhD; Fang Wang, MS, Haitao Pan, PhD, Jane S. Hankins, MD, MS

Development, Feasibility, and Acceptability of an EMR-based Transition Readiness Assessment: A Cerner Adaptation of the UNC Transition Index
Lauren Partain, LCSW; Erin Benekos, NP; Wendy Gray, PhD; Kenneth Grant, MD; Hanae Kim, MHA; Michelle Kennedy, LCSW; Karina Chavez, LCSW; Mark Daniels, MD; Donald Phillips, MD; Lilibeth Torno, MD; Michael Weiss, MD

Youth Engagement with Patient Navigator During COVID-19
Zoya Punjwani, MPH; Ken Pfister, MSc; Daniella San Martin-Feeney, MSc; Brooke Allemang, MSW, RSW; Laurel Ryan, MFA; Gina Dimitropoulos, PhD, RSW; Susan Samuel, MD

2:45 PM Break

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Participants will have access to view posters beginning early October with website links available upon registration. During Session 1, topical breakout sessions will be available to query panels of poster presenters about their work.

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Research Symposium Abstracts	
Platform Session 1: Health Care Transition: International Perspectives	
Presentation 1	<p>Transitional Care in Rheumatology: Current Practice in Switzerland <i>Berben Lut, PhD, RN; Sigg Nor, MD; Daly Mary Louise MSc, RN; Bachmann Stefan MD; Baer Walter MD; Berthet Gérald MD; Bolt Isabel MD; Dan Diana MD; Enderlin Steiger Susanna MD; Fröhlich Johannes MD; Hasler Paul MD; Hofer Michaël, MD; Huemer Christian MD; Kaiser Daniela MD; Marcoli Natalie MD; Palmer Sarott Seraina MD; Rottländer Yella MD; Schmid Gernot MD; Soennichsen Christa RN; Strahm Furler Laura MScN, RN; Vanoni Federica MD; Wildi Lukas MD; Daikeler Thomas MD; Woerner Andreas MD</i></p> <p>Background: About half of all children with rheumatic diseases need continuous medical care during adolescence and adulthood. A good transition into adult rheumatology is essential. A structured transition</p>

	<p>process has therefore been recommended by the European League Against Rheumatism (EULAR) and the Pediatric Rheumatology European Society (PReS). However, these recommendations are not widely implemented. The aims of the investigation is to assess the current practice of transitional care (TC) in Switzerland in relation to EULAR/PReS recommendations and to describe gaps and challenges in following the recommendations.</p> <p>Methods: All ten pediatric Swiss rheumatology centers and their collaborating adult centers offering transition service to adult care were invited to participate. The responsible pediatric (n= 10) and adult (n= 10) rheumatologist of each center was interviewed separately using a structured manual addressing the EULAR/PReS transitional care recommendations.</p> <p>Results: All centers implemented parts of the recommendations, however none of the centers implemented all recommendations. Whereas some recommendations were given in all centers: e.g. continuity in healthcare team, consultations focused on adolescents and young adults, and joint consultations between pediatric and adult rheumatologists, other were only implemented in some: e.g. multi-disciplinary approach, the transfer to other disciplines at the same time, defined age for initiating transition and the existence of a transition plan. Despite this, most centers rated the performance of their TC as very good. The participants reported that they do not face major barriers that hinder the implementation of the recommendations.</p> <p>Conclusion: This survey provides evidence on the current structure of TC in Swiss rheumatology centers. The impact of this heterogeneity of TC in Switzerland on young adults' clinical outcomes across centers can be essential. Next, we will study long-term disease outcome of young adults together with the evaluation of patient reported outcomes (e.g. quality-of-life, satisfaction with care) in relationship to the implementation of the EULAR/PReS recommendations.</p>
Presentation 2	<p>Healthcare Transition Preparation in Adolescents with Kidney Transplantation or Pretransplant in Cali Colombia <i>Jaime Restrepo MD; Maria Alejandra Agredo MD; Lina María Viafara MD; María Santa Santamaría; Angela Mantilla; María González; Adriana Palacio; Jhovana Trejos; Hernando Londoño MD; María Ferris MD PhD; Mara Medeiros MD PhD</i></p> <p>Background: Graft survival and health-related quality of life (HRQoL) in pediatric kidney transplantation have improved in the last 20 years due to better treatment, surgical techniques, and a closer interdisciplinary follow-up. We observed an increase of graft loss in the transition from pediatric- to adult-focused settings, due to new challenges related to age, sexual activity, and trouble with parents' authority. Adolescents exhibit low adherence to treatment and putting at risk the survival graft and HRQoL. Fundación Valle del Lili, in collaboration with the STARx Program at the University of North Carolina Chapel Hill and the HIMFG, started a transition preparation program in order to improve this process. The objective of this study was to describe the implementation of a transition program and to evaluate its effect on health care transition preparation and self-management among adolescents with kidney transplantation or in a pre-transplant state.</p> <p>Methods: We performed a quasi-experimental intervention study in all pre- or transplant patients ages 11-19 years, followed by our Pediatric Nephrology Service. Using the TRxANSITION Index, we evaluated disease knowledge and self-management skills before and after a transition educational curriculum delivered in three, 2-hr. sessions. This Index has a maximum score of 10, We performed descriptive analysis and Student's T-test, using the STATA program version 12.1.</p> <p>Results: We enrolled 35 participants, 54% males, mean age 14.8 ± 2,3 years and 57% had congenital anomalies of the kidneys and urinary tract as the main diagnosis The baseline global score was 5.87±1.96 and post-test was 8.98 ± 0.82 (p-value =0.00). All areas of the Index showed significant increases. The highest increase was noted on the "Find a new provider" (0.53), followed by "Issues of reproduction (0.51), "Health insurance" and "Type of illness" (0.34).</p> <p>Conclusions: The Colombian adaptation of the STARx program with its interventions and tool to measure transition (TRxANSITION Index), significantly improved adolescents' disease knowledge, self-management, and healthcare transition preparation. Longitudinal observations are underway to determine the persistence of this effect and its potential impact on HRQoL and adherence.</p>
Presentation 3	<p>Healthcare Transition Readiness Self-report Tool: Translation, Cultural Adaptation, and Linguistic Validation of the STARX Questionnaire – Russian Version <i>Elena Kulakova, MD, PhD, NN; Tatjana Nastausheva, MD, PhD; Oleh Akchurin, MD; Maria Koltakova, MD, NN; Tatjana Zvyagina, MD, PhD, NN; Anastasija Ledovskih, MD, NN; Maria Diaz-Gonzalez de Ferris, MD, MPH, PhD</i></p> <p>Background: A planned healthcare transition (HCT) allows adolescents to achieve better outcomes. The development of targeted strategies to facilitate HCT requires a measurement of transition readiness. In this study, we adapted and validated for Russian adolescents the well-known STARX (Self-Management and Transition to Adulthood with RX = Treatment) Questionnaire.</p> <p>Methods: The STARX Questionnaire is a disease-neutral, 18-item self-report tool that measures HCT readiness among adolescents with chronic conditions. The maximum score is 90. We conducted cultural</p>

	<p>adaptation, and linguistic validation of this tool, by using two-step (forward-backward) translations, reconciliation, revision, cognitive interviewing, pilot testing, final review, and proofreading. This process was carried out by an international multidisciplinary team.</p> <p>Results: The STARX Questionnaire – Russian test version was developed through the iterative process of translation/back translation and cultural adaptation. The test version was used for cognitive interviewing with 5 adolescents. The input obtained from participants helped to improve 8 items. For the pilot testing phase, the STARX Questionnaire – Russian version was administered to 30 patients with chronic kidney disease (CKD) and 15 patients with type 1 diabetes mellitus (DM) ages 15 to 17. The total median STARX Questionnaire - Russian version score was 69.0 (IQR 61.0-71.0) in adolescents with CKD and 75.5 (IQR 65.0 – 77.5) in adolescents with DM (p=0.2). During the pilot testing, adolescents demonstrated an excellent understanding of all items which was confirmed by post-survey interviewing.</p> <p>Conclusions: In this study, we developed a Russian HCT readiness self-report tool, based on the STARX Questionnaire. The total scores represent a low to moderate HCT readiness among participants. The STARX Questionnaire – Russian version appears to be a promising measure to guide targeted interventions in order to improve HCT preparation and patient outcomes.</p>
Presentation 4	<p>Using Storytelling to Amplify Voices of Those Who Transitioned Through Healthcare (Scotland) <i>Sharon Levy MPhil RN; Iona Campbell, BS</i></p> <p>Introduction: Our project amplifies the voices of individuals and their support network on their experiences of the transition into adult healthcare. We have used storytelling as a qualitative method of eliciting data (stories) from participants which can be used to educate healthcare professionals on how transition feels for those actually going through it. These stories will be digitalised and become part of an online learning platform about transitions which is in the earlier stages of creation.</p> <p>Methods: Over Zoom, we held three collaborative storytelling workshops facilitated by RealTalk, a storytelling organisation, to move through the processes of constructing, honing and telling a good story. Our participants consisted of eight people who had either been through, or supported someone else through, transition. The sample included people from across Scotland, most of which had unique experiences of transition through different healthcare boards. The first workshop was an opportunity to brainstorm ideas, the second was to create a clear storyboard of their transition journey and in the third workshop participants learned about storytelling techniques. We are currently in the process of digitally recording each participants telling their story.</p> <p>Results: The outcome of this project has been five digital stories co-produced with our participants. Each 'digital story' will include audio of the individual telling their transition story with photos laid over which reflect their experiences. will be added to our online learning hub for healthcare professionals and also be made accessible to a wider audience through YouTube. As an organisation we have gained further insight into the individual experience of transition.</p> <p>Conclusion: Successful production of these digital stories has provided a robust resource through which healthcare professionals can educate themselves and their peers about the realities of this transition process for young people and their support network.</p>
Presentation 5	<p>Transition Navigator Trial: Evaluating the Impact of a Patient Navigator on Health Care Utilization by Youth with Chronic Disease Transitioning to Adult Care (Canada) <i>Susan Samuel, MD, MSc; Gina Dimitropoulos, PhD, RSW; Andrew Mackie, MD, MSc; Alberto Nettel-Aguirre, PhD; Daniele Pacaud, MD; Greg Guilcher, MD; Jorge Pinzon, MD; Eddy Lang, MD; Gail Andrew, MD; Lonnie Zwaigenbaum; Shannon Scott, RN PhD; Scott Klarenbach, MD, MSc; Lorraine Hamiwka, MD; Brooke Allemang, MSW, PhD (candidate); Kristin Tinge, BSW; Ken Pfister, MSc; Daniella San Martin Feeney, MSc</i></p> <p>Background: Transitional care between pediatric and adult services is variable and may result in increased use of emergency services and adverse health outcomes. The Transition Navigator Trial aims to evaluate the effectiveness of a patient navigator service to decrease emergency room (ER) use and improve overall experience of youth with chronic disease who are transitioning to adult care.</p> <p>Method: We are conducting a province-wide pragmatic randomized controlled trial to evaluate the effectiveness of a patient navigator versus usual care in patients aged 16 – 21 years old with a chronic condition who are transferring to adult care. The navigator role was developed after extensive stakeholder consultation and interviews with patients and families. The navigator will facilitate a planned transition by coordinating care, promoting self-management skill development and addressing barriers to care. Poisson regression will be used to compare rates of ER/urgent care visits between groups.</p> <p>Results: Recruitment began in January 2018. 321 patients have been enrolled with 144 patients randomized to the navigator arm, 165 randomized to usual care arm, and 12 withdrawals. The median enrollment age is 17.5 years. Of these patients, 44% are males, 54% are females and 2% other gender identities. Of the 321 participants enrolled, 75% identify as Caucasian, 10% First Nation/indigenous, 10% Asian, 2% Black, and 3% other ethnicities. The study has experienced challenges in recruitment related to characteristics of the population under study, and the COVID-19 pandemic. During this time, navigators have adapted their role to</p>

	<p>provide service virtually and in settings outside of a traditional care environment. We expect that the navigator intervention will improve overall care experience and decrease urgent care use among young adults. Conclusion: This study will provide data to guide providers and policy makers regarding optimal transitional care and benefit the growing population of young adults with chronic health conditions.</p>
BREAK	
Platform Session 2: Continuous Quality Improvement/Program Development Models of Care/Other	
Moderator:	
Presentation 1	<p>Comprehensive Transition Program at a Free-Standing Pediatric Hospital: Demonstrating Impact Utilizing the Current Assessment of Healthcare Transition Activities <i>Susan Shanske, MSW, LICSW; Suzanne Dahlberg, PhD; Leanne Langmaid, MSN, RN; Jamara Polzin, MSW; Colleen Huysman, MSW, LICSW; Julia Roboff, MSN, FNP-BC, CPN; Nadia Abdulrazak, MSN, ANP-C; Rebecca Berger, FNP; Samantha Covelle, MSN FNP-BC; Cassandra Fleurentin, FNP-BC; Nancy DiTullio, FNP; Kitty O'Hare, MD; Niraj Sharma, MD, MPH; Leah Ratner, MD, MS; Ahmet Uluer, DO, MPH</i></p> <p>Background: Pediatric hospitals can facilitate transitional care by allocating resources to programs designed to serve individual patients and programmatically create institutional change. An inpatient and ambulatory transition program with a strong educational and coaching component was established to address transition at a large freestanding children's hospital.</p> <p>Methods: To evaluate the impact of the transition program, established by Boston Children's Hospital (BCH) in October 2013, serial surveys using GotTransition's "Current Assessment of Healthcare Transition Activities" were deployed. The initial assessment in 2014 was sent to major divisions with only 17 responses completed. For more detailed understanding, program-level surveys were sent in 2017 and 2020, with BCH providers rating themselves across 6 domains, measured on categorical scales from 1-4. Of 195 records available, 27 were removed from analysis due to multiple respondents from the same program or not having paired responses, leaving 168 paired records from a total of 84 BCH programs. The Madansky test measured whether the responses changed over time and the Wilcoxon signed rank test was used to compare total scores.</p> <p>Results: The assessment is based on 6 domains (Transition Policy/Guide, Tracking and Monitoring, Readiness, Planning, Transfer, Transition Completion) with additional questions added in 2020. The change in categorical scale (1-4, from least prepared to fully prepared) was measured for each domain. Comparison of paired scores from 2017 and 2020 revealed a statistically significant change in response involving three domains: Policy/Guide (p=0.009), Readiness (p=0.01), Planning (p<0.001), while the remaining domains only approached significance. The median total score was 9 (range 7-12) and 11 (range 8-13) on 2017 and 2020, respectively (p=0.001).</p> <p>Conclusion: The BCH Bridges Adult Transition Program demonstrated institutional change through broad clinical and educational efforts in a large freestanding children's hospital as evidenced by statistically significant differences reported on the "Current Assessment of Transition Activities".</p>
Presentation 2	<p>Health Care Transition in State Public Health Programs: A Review of Current State Title V Block Grant Reports <i>Samhita Ilango, MSPH; Peggy McManus, MHS; Dan Beck, MA; Patience White, MD, MA</i></p> <p>Background: In 2021, 32 states and 4 jurisdictions (District of Columbia, Guam, Marshall Islands, and the Northern Mariana Islands) selected National Performance Measure (NPM) 12 focused on health care transition (HCT) as a priority NPMs. While significant HCT efforts have been undertaken by state Title V agencies, the 2018/19 National Survey of Children's Health revealed that though there have been small improvements, there is still a need for continued attention to HCT. Parents reported that 77% of their youth with special health care needs and 83% of their youth without special health care needs did not receive HCT preparation from their health care providers.</p> <p>Methods: Got Transition systematically analyzed the 2021 State Title V Block Grant Applications/2019 Annual Reports from each of the 32 states and DC to identify innovative HCT strategies related to addressing racial/ethnic and geographic disparities; youth and family leadership development and education; state interagency transition efforts; health care professional education and policy developments; quality improvement efforts; collaboration with school health; communication and social media, and alignment with related NPMs. The abstracted data were compared to a similar 2018 analysis. A set of recommendations for strengthening transition objectives, evidence-informed strategies, and measurement approaches were also formulated.</p> <p>Results: Data will be presented on state public health transition initiatives, including innovative strategies from the 2021 State Title V Block Grant Applications/2019 Annual Reports. (Note: we are currently completing this analysis.)The findings of this analysis demonstrate widespread use of the Six Core Elements as part of state public health initiatives to address HCT.</p>

	<p>Conclusions: The findings of this analysis highlight current state HCT initiatives, changes from 2018, and recommendation for states to address HCT needs of youth/young adults and their families. The findings also underscore potential areas of opportunity for collaboration between clinical and public health systems."</p>
Presentation 3	<p>The Use of the "Transition Map" in Care Coordination for the Transitional Patient <i>Samantha Covelle FNP, BC; Colleen Huysman LICSW, Leanne Langmaid RN MSN</i></p> <p>Background: The BRIDGES Adult Transition Program (BAT) at Boston Children's Hospital (BCH) provides age appropriate medical care, and transition coordination and preparedness to young adult patients with chronic and complex medical disease. We offer outpatient transition visits with our multidisciplinary team including a physician, nurse practitioner, nurse transition coordinator and social worker. The nurse practitioner facilitates communication between the pediatric to adult care teams through the development of a "transition map.</p> <p>Methods: The transition map is a working document that encompasses the patient's care team by specialty. Each column includes 1.) the active provider 2.) diagnoses the provider is responsible for 3.) medications they prescribe and, 4.) individual transition plan including recommendations for an adult provider based on their needs. Other considerations when identifying new providers include insurance and minimizing adult care under one hospital system to optimize communication. BRIDGES nurse practitioners perform extensive chart reviews and outreach to active providers to compile information within the transition map.</p> <p>Results: The transition map is uploaded to the patient's electronic medical record and is included in the transfer packet to new providers. This map provides valuable information pertaining to one's transition plans especially when some patients may continue to see both pediatric and adult providers across different institutions, as well as determining where future admission should take place. To date, BRIDGES has completed over 240 visits with over 100 unique patients.</p> <p>Conclusion: The transition map is a live document that concisely displays all members of our patients' care team with their future transition plan. This document serves as a communication tool between the BRIDGES multidisciplinary team, patient/family, and current/ future care teams. An important next step includes administering a survey assessing the usefulness amongst both pediatric and adult providers.</p>
Presentation 4	<p>Bridging the Transition Gap; Developing a Transition Program Using QI Methodology <i>Unoma Akamagwuna, MD, Jensine' Norman, MD</i></p> <p>Background: Cerebral Palsy (CP) is the most common childhood disability. Many patients and families meet their pediatric rehabilitation provider early in life and may remain with the same provider for several years. This strong relationship can make transition to a new adult provider difficult. There is not a standardized process to identify adult providers, navigate insurance changes or inform families about resources. We set out to develop and implement a transition pathway to address the barriers that patients face in addition to remaining family-centered.</p> <p>Methods: There are a total of 1861 patients with the diagnosis of CP followed in our department. Of that we have 389 patents who are age 18 and over (21%) and 149 patients (8%) of our population who are age 21. We set a primary aim to standardize the process for transition of patients with the diagnosis of Cerebral Palsy from pediatric to adult rehabilitation medical practice by provision of a pathway in addition to increasing provider knowledge of the process and available resources and successfully transitioning at least 30% of our eligible patients.</p> <p>Results: Since September of 2020 we have successfully transitioned 35% of our transition eligible patients, in addition we have established a sustained system of transition within the physical medicine and rehabilitation medicine clinic</p> <p>Conclusion: Quality Improvement methodology can serve as an effective framework to use to build a transition program and would be suggested for programs endeavoring to build a program as it allows for rapid cycle changes and engagement of key stakeholders.</p>
Presentation 5	<p>Massachusetts Initiative to Improve Transition to Adult Healthcare for Individuals with Neurodevelopmental Disabilities (NDD): Phase 2 <i>Susan Shanske, LICSW; Sarah Spence, MD, PhD; Jamara Polzin, MSW; Lindsay Hunt, MEd</i></p> <p>Background: Youth with neurodevelopmental disabilities (NDD) face unique challenges with healthcare transition^{1,2,3}. They may lack access to care and experience poorer health outcomes⁴. While Massachusetts has been doing better than the national average on transition related measures,⁵ attention must be paid to this vulnerable population.</p> <p>Methods: The Massachusetts Initiative to Improve Healthcare Transition for Individuals with NDD started in 2018, pulling together key stakeholders to examine drivers for improvement and engage in solution- oriented collaboration. Months of task force research and brainstorming concluded with a statewide summit in 2020.</p>

	<p>Results: Nearly 200 people participated in the summit which had three primary objectives: 1. Identify models for best practice in pediatric to adult care transition for individuals with NDD in Massachusetts; 2. Describe quality improvement strategies to implement changes in practice; 3. Engage in solution-focused collaboration with stakeholders across Massachusetts. 100% of respondents (n=65) stated that all objectives of the summit were met. 95% rated the summit overall as very good or excellent; 80% reported that the summit was helpful or very helpful in setting transition related goals. Initiative members, including steering committee and task forces, rated their experience of participation. All respondents (n=27) were neutral to very satisfied and all indicated they felt neutral to very good about the use of their time. 26 out of 27 respondents said that they felt they contributed to overall initiative objectives and 24 of 26 wanted to hear about continued opportunities for engagement.</p> <p>Conclusions: Engaging stakeholders across Massachusetts in efforts to improve transition to adult healthcare for the vulnerable population of people with NDD yielded positive momentum and a sense of community. Phase 2 utilizes an innovation collaborative approach from QI methodology, with teams of pediatric providers, adult providers and patient/family partners working together to test change ideas developed in the initiative.</p>
BREAK	
POSTER SESSION 1	
Group 1: Continuous Quality Improvement/Program Development/Models of Care	
Poster 1	<p>Youth-Engaged Transition Research in Alberta: Successes, Challenges & Lessons Learned <i>Brooke Allemang, MSW, RSW; Megan Patton; Guelph Humber; Gina Dimitropoulos, PhD, RSW, Zoya Punjwani, MSc; Daniella San-Martin Feeney, MSc, Laurel Ryan, MFA, Susan Samuel, MD</i></p> <p>Background: The process of engaging youth in research during the transition from pediatric to adult services is unique based on the developmental milestones associated with this period (i.e., newfound independence, frequent moves, changes to schedules). It is crucial that the needs and preferences of young people during this transition period be considered and that adaptations be made during the pandemic.</p> <p>Methods: A multidisciplinary research team is conducting 3 province-wide studies focused on the transition from pediatric to adult services in Alberta, Canada. With over 350 youth collectively enrolled in these studies, we are using administrative data, clinical data, and qualitative data to obtain a well-rounded perspective of the transition process and experience for Albertans. In order to ensure data is being interpreted and presented in meaningful ways, an overarching youth and family advisory council is being developed.</p> <p>Results: We will present successes, challenges and lessons learned from conducting youth-engaged health transition research. Adjustments to youth advisory council consultations have been made in light of the pandemic, including a shift to virtual platforms. Challenges have included inequitable access to technology, recruitment of those from diverse backgrounds, and added stressors on youth and families during the pandemic. Lessons learned include the importance of compensation, meeting young people where they are at and being flexible.</p> <p>Conclusions: Engaging individuals with lived experience in research and program development during the transition period contributes to more relevant, impactful and meaningful projects aligning with the needs of youth and families. The nuances of the transition period require that flexibility and accommodations be considered in order to best conduct youth-engaged research.</p>
Poster 2	<p>Health Care Transition for Children with Medical Complexity <i>Megan Teed, DNP, RN, FNP-BC, APNP; Allison Bekx, BSN, RN, CPN; Molly Paul, BSN, RN, CPN; Lauren Younker, BSN, RN, CPN</i></p> <p>Background: Transition from pediatric to adult health care is a pivotal process for young adults, especially those with complex medical needs. Despite advancements in the medical care provided to children with medical complexity (CMC), there is a lack of systematic approaches and guidance for patients and families transitioning from pediatric to adult health care.</p> <p>Methods: Health care providers and nurse case managers in the Complex Care Program (CCP) evaluated health care transition practices prior to 2019, and initiated quality improvement efforts to standardize transition guidance, planning, and documentation from 2019-2020 within the CCP. Currently the CCP has approximately 700 patients, of which 20% are twelve years old or older.</p> <p>Results: Challenges identified with transitioning CMC include: 1) Varied approaches and timelines for health care providers, 2) Documentation in the EMR, and 3) Connecting to adult health care systems. Throughout this work, CCP staff have learned lessons to effectively transition CMC. Themes included: 1) Transition from a pediatric to an adult primary care provider first, 2) Start transition conversations early, 3) Identify a universal location to document transition planning, and 4) Importance of family involvement.</p> <p>Conclusion: To effectively transition CMC, health care staff must start conversations early, engaging all primary and specialty providers, patients, and families to create safe transition plans.</p>
Poster 3	<p>Assessment of Got Transition's 6 Core Elements in primary and subspecialty care: A health network-wide evaluation of current state, early adopters, and future opportunities</p>

	<p><i>Wendy N. Gray, PhD; Parasto Dorriz, MHA; Erin Benekos, NP; Lauren Partain, LCSW; Hanae Kim; Mary Zupanc, MD; Michael Weiss, MD</i></p> <p>Background: A current state assessment of Got Transition's 6 Core Elements was conducted to: 1) establish a baseline against which to evaluate our future progress, and 2) identify and learning from early implementers of transition programming currently operating within siloes.</p> <p>Methods: Got Transition's Health Care Transition Process Measurement Tool was distributed via REDCap and completed by 112 providers representing primary care and 10 subspecialty divisions. Data were aggregated by division and scored by "level" according to Got Transition's Current Assessment of Health Care Transition Activities rubric.</p> <p>Results: Most practices were scored in the Level 1 category across Got Transition's 6 Core Elements. The average age at which transition is introduced varies widely, with no significant difference between primary or subspecialty care (X = 13.68 years, Range = 1-20 years). Very few practices have a formal process for identifying, tracking, assessing, or educating transition-aged youth. Primary care practices uniformly met with youth, to meet alone with their provider, but this was less common in subspecialty clinics. Endocrinology stood out amongst all clinics as a leader in implementing the 6 Core Elements yet no single specialty clinic was fully compliant.</p> <p>Conclusion(s): Although implementation of Got Transition's 6 Core Elements is generally low across our institution, a small number of divisions and individual providers are incorporating elements of a structured transition process into their visits. To date, no division/clinic is fully implementing all 6 Core Elements. These baseline data will serve as a comparison point for future institution-wide efforts to implement a structured transition program.</p>
Poster 4	<p>BRIDGES Virtual Transition Clinic: 1 Year Later <i>Leanne Langmaid MSN, RN, CPN; Leah Ratner MD, MS, DTM&H; Colleen Huysman MSW, LICSW; Ahmet Uluer DO, MPH</i></p> <p>Background: The BRIDGES Adult Transition Program at Boston Children's Hospital provides transition consults to young adults with chronic and complex medical disease. In response to the COVID-19 pandemic, a virtual platform and subsequent process was developed to best support young adults facing new vulnerabilities within an overburdened system. BRIDGES has been offering these visits for over a year now.</p> <p>Methods: Patients over the age of 18 with at least one pediatric onset illness and three chronic morbidities, actively managed by subspecialists and/or psychosocial vulnerabilities meet inclusion criteria. The multidisciplinary team includes an internal medicine - pediatrics physician, nurse practitioner, nurse transition coordinator and social worker. Our process highlights the uniqueness of each patient and aims to understand lived experience to further recognize barriers while defragmenting care. BRIDGES collaborates with the patient's active care team to identify adult primary and specialty providers, insurance considerations, self-management skill development, decision making considerations and community resource referrals.</p> <p>Results: BRIDGES has completed over 230 virtual visits, with 96 unique patients between March 2020-April 2021. On pre-survey, using 0-10 Likert scale, an average score of 5.4 was assigned when asked 'how comfortable are you with transition planning' (N=42). During this time BRIDGES has graduated 22 patients who have successfully transitioned, with another 13 patients anticipated to discharge after their next visit. Post data focusing on overall experience for both patients and referring providers is needed to assess whether BRIDGES' process is meeting anticipated goals and outcomes.</p> <p>Conclusion: Young adults with complex chronic medical conditions require comprehensive individualized support to address unique needs related to their diagnoses, psychosocial vulnerabilities and ability to navigate the healthcare system. BRIDGES provides imperative individualized advocacy, recognizing that those currently on the margins receive less. A multidisciplinary team can best address unique patient needs that impact one's ability to successfully transfer care.</p>
Poster 5	<p>Development and Implementation of a Comprehensive Pediatric Cardiology Transition Program <i>Navreet Gill, RN, MN; Sandra Aiello, RN; Conall Morgan, MB BCh BaO FRCPC; Rafael Alonso-Gonzalez, MD, MSc</i></p> <p>Background: More than 90% of children born with congenital heart disease (CHD) are now surviving into adulthood, necessitating life-long follow up with an adult CHD specialist. Unfortunately, there exists a lack of structured programs to support adolescents in the transition from pediatric to adult cardiac care, resulting in delayed care, emotional distress, patients lost to follow up and ultimately delayed recognition of cardiac complications. To address this need a cardiac transition program for adolescents with CHD, aged 14 to 17 years old, was developed and implemented within the Labatt Family Heart Centre at SickKids.</p> <p>Methods: The pediatric cardiac transition program was established in conjunction with the Adult Congenital Cardiac Program at the University Health Network Peter Munk Cardiac Centre, using both a quality improvement process and Got Transition's Six Core Elements of Health Care Transition™ approach.</p> <p>Results: Program development included creation of an organizational cardiac transition policy, transition registry, epic-integrated transition flowsheet, and transfer checklist. Program implementation consisted of delivering in-person and/or virtual, nurse-led, one-on-one clinic sessions with a focus on CHD disease-specific education, self-</p>

	<p>management behaviours and self-advocacy skills. Adolescent patients are assessed on their cardiac knowledge, transition readiness, and quality of life and are screened for both anxiety and depression. With each transition session adolescents are encouraged to gradually embrace greater responsibility in their healthcare management over time, to facilitate ownership of their health.</p> <p>Conclusions: Development and implementation of the cardiac transition program are the first steps towards improving the transition experience of adolescents with CHD. Future endeavours include development of parent-focused transition sessions, program expansion to include patients aged 12 – 25 years old, and the evaluation of the program’s impact on patient transition readiness, satisfaction, CHD knowledge and patient transfer experiences post-transfer (i.e., time to first adult cardiac appointment, adult cardiac clinic attendance, and frequency of unplanned cardiac procedures).</p>
Poster 6	<p>Impact of Transition Planning and Implementation of a Transition Policy and Procedure on Successful Transition from a Pediatric HIV Clinic <i>Sara Aguirre, LMSW; Susan Gillespie, MD, PhD; Albert Hergenroeder, MD; Gayatri Mirani, MD; Eduardo Ocampo, MA; Mary Paul, MD; Gloria Sierra, MPH</i></p> <p>Background: The process and execution of transitioning people living with HIV (PLWH) is critical in continuing care throughout adulthood. The transition from pediatric to adult medical care can be challenging. The process of transition includes educating the PLWH and their family, working together on a transition agreement plan, and completing each goal until the first visit with an adult provider.</p> <p>Methods: From 2017-2019 there were 49 PLWH who transitioned to adult care. From 2019-present, there have been 31 PLWH who have transitioned or currently in process of transitioning. In 2019, a transition process was created and utilized with PLWH through a Patient Navigator (PN). The transition policy and procedure is reviewed every quarter with a multidisciplinary team. In the last two years, the following has been implemented: 1. Transition Policy 2. Transition Planning Agreement 3. Transition Timeline 4. Transition Folder including map of HIV adult-based clinics, PN description of role and contact information, certificate of completion, and information on transportation assistance 5. Transition Planning Tool 6. Transition Closure Form.</p> <p>Results: Since 2019, there have been 14 successful transitions to adult care. There are currently 17 PLWH in process of transitioning. From 2017-2019, there were 49 PLWH who transitioned without a documented process or procedure. There are 11 PLWH with uncertain transition status. There are 38 PLWH with some documentation of transition.</p> <p>Conclusion(s): A key component to successful transition is a strong policy and procedure. The role of implementing the transition policy and procedure is essential is keeping PLWH in care as they become adults.</p>
Poster 7	<p>Implementation of a Web-based Transition to Adult Care Program for Adolescents with Congenital Heart Disease <i>Blakelee Wright, DNP, APRN, CPNP-AC/PC; Susan Connelly, DNP, APRN-NP</i></p> <p>Background: CHD affects 1.35 million newborns annually. With medical advances, these children are surviving into adulthood. Approximately 1.4 million adults live with CHD and less than 10% receive proper care. There are limited structured transition programs promoting successful transition to adult care. Morbidity and mortality increase with inconsistent transition processes. The purpose of this Quality Improvement (QI) project was to evaluate confidence and engagement in an inpatient transition process for adolescents with Congenital Heart Disease (CHD). Education was supplemented with a web-based application to provide text-message- coaching.</p> <p>Methods: The sample consisted of adolescents with CHD on a 23-bed medical surgical unit specializing in pediatric cardiology at a Midwestern Children’s Hospital between September 2020–November 2020. Evaluated using a pre-/post-survey. Education was provided using a standardized binder. Following inpatient education, participants received text message coaching over a 3- week period via a web-based application (OhMD). This project evaluated two questions pertaining to engagement and confidence in the transition process and asked participants to rate responses on a 0–10 scale. A score of 5 was the predetermined indicator for engagement and confidence.</p> <p>Results: 2 of 6 participants completed the post-survey, yielding a 33% response rate. No respondents’ engagement scores were ≥ 5 on the pre-survey; however, all demonstrated increased engagement on the post-survey. 33% of respondents’ confidence scores were ≥ 5 on the pre-survey; however, all indicated decreased confidence on the post-survey. Of the 33%, half of respondents agreed text messages were helpful in progressing towards their transition- centered goal, and text messages and/or the use of a web-based application would be beneficial in the transition process.</p> <p>Conclusion: Text-message-coaching and/or a web-based application suggests promise in the transition process for adolescents with CHD. Further studies with larger sample sizes are needed to determine sustainability and effectiveness of inpatient transition education and the use of a web-based application, in promoting engagement and confidence in the transition process.</p>
Poster 8	<p>Improving Transition Education for Underserved Youth with Sickle Cell Disease <i>Dhanashree Bahulekar, BA; Abbe Hurt; Aimee W. Smith, PhD</i></p>

	<p>Background: The transition from pediatric healthcare to adult healthcare can be difficult for youth with sickle cell disease. An unsuccessful transition can result in worsening disease status (e.g., pain crises), increased healthcare utilization (e.g., more emergency room visits), and poor quality of life. The aim of the current study was to develop transition program materials to improve healthcare transition for a regional comprehensive sickle cell clinic. We describe our steps and preliminary results from this process including 1) identifying the areas of need for transition education, 2) deciding the format and deliverables for training, and 3) finalizing deliverables using feedback from patients, their caregivers, and medical professionals.</p> <p>Methods: The areas of need for transition education were determined through consultation with the sickle cell medical team. These areas were refined and aligned with the Sickle Cell Transition Intervention Program (TIP) (Treadwell et al, 2011). Formats for training included infographic-style handouts, a website, and brief videos. Drafts of deliverables were shown to 10 patients (>12years old), their caregivers (n=10), and 5 medical professionals who care for sickle cell patients via interview or focus group for feedback.</p> <p>Results: Important themes for deliverables included the patient's knowledge surrounding their diagnosis, social support, and self-efficacy concerning the transition process. Examples of deliverables will be included in the poster. Feedback on the deliverables from patients, their caregivers, and medical professionals will be reported.</p> <p>Conclusion: This project describes a process of developing and refining transition education materials for youth with sickle cell disease. Using the transition education components, we can work towards improving their understanding of sickle cell disease and readiness to transfer to adult care. The final deliverables will be refined according to the feedback received through the focus groups from this project before being integrated into regular clinic practice.</p>
Group 2: Adolescents/Emerging Adults/Family Experiences	
Poster 1	<p>Transition and Spina Bifida: A Collaborative Boardgame about Transition <i>Iona Campbell, BS; Sharon Levy MPhil, RN</i></p> <p>Introduction: Our innovative project, built off previous work, articulates the challenges young people with Spina bifida and Hydrocephalus face, as they progress to adult healthcare services. Using carefully facilitated virtual GameJam setup, we co-produced a collaborative gameboard that was tested and further honed by younger participants and healthcare staff in subsequent sessions. The printable game engages families and healthcare staff, through a playful interaction, and creates an opportunity to explore and prepare for the transfer of care to adult centred services.</p> <p>Methods: We brought families from across the UK together via Zoom; including five young people and their parents, to discuss this creative way in which they can support others who are going through a transition process. In the initial meeting we spent time on getting to know each-other, introduced the overall aim of the project and explored what makes an engaging boardgame. In the following weekly one-hour sessions, we agreed the overall aim, core rules and mechanics of the game. With the help of a graphic designer, the cards and a cooperative setup were transformed to tangible assets. The beta version of the game was played in a final session before testing was expanded to aid refinement of usability and design elements for home printing.</p> <p>Results: The outcome is a cocreated transition boardgame, which can be played by anyone involved in the process of transitioning from paediatric to adult healthcare services. The cards are easily printed at home or work and include detailed instructions for collaborative play. Testing demonstrated that players collaborated to find solutions for potential challenges and discussed how these relate to their own experience and practice.</p> <p>Conclusion: Co-production of a game to support the process of transition proved to be a useful and cost-effective means to engage stakeholders in a meaningful and purposeful way.</p>
Poster 2	<p>Preliminary Results of Analysis of Transition Navigator Trial Interviews <i>Megan Patton: Nikki Cheslock, BSW; Sophie Samborn, BSW, RSW; Zoya Punjwani, MPH; Ken Pfister, MSc; Daniella San Martin-Feeney, MSc; Brooke Allemang, MSW, RSW; Andrew Mackie, MD; Susan Samuel, MD; Gina Dimitropoulos, PhD, RSW</i></p> <p>Background: The transition from pediatric to adult care can be challenging for young adults with chronic health conditions, and can contribute to adverse outcomes and lack of continuity of care. The Transition Navigator Trial (TNT) is a randomized control trial being conducted in Alberta, Canada, recruiting from 3 major tertiary care pediatric centers, in which half of participants receive a patient navigator, whose goal is to assist with this transition.</p> <p>Method: Participants were interviewed at baseline about their perspectives on the upcoming transition and how working with the navigator may assist with the transfer of care to adult focused services. 48 interviews were conducted at baseline, with a planned follow-up interview at the end of trial. A thematic analysis with an inductive approach was undertaken following the recommendations of Braun and Clarke (2006). Emerging themes are based on the analysis of the first five baseline interviews.</p> <p>Results: 48 interviews (24 male, 21 female, 3 other genders; average age 17) were conducted. Emerging themes are as follows: the change in perspective on the patient navigator role pre and post baseline interview, mixed emotions such as fear and excitement regarding the transfer from pediatric to adult care, comparison of lived experiences to others with similar diagnoses and past selves, resiliency in the face of adversity with a chronic</p>

	<p>condition, coping during a pandemic, and hopes of gaining independence and self-advocacy skills after working with the patient navigator.</p> <p>Conclusion: We expect that our results will inform the practitioners on how to enhance patient navigator interventions and assist healthcare professionals working in pediatric and adult services how to support this age group. The findings will further influence research on transition interventions for other populations, such as those with mental health concerns</p>
Poster 3	<p>Transition to Adulthood: Experience of Youth With Spina Bifida in Japan <i>Shiho Murayama, PhD; Jennifer J. Doering, PhD, RN; Kathleen J. Sawin, PhD, CPNP-PC, FAAN</i></p> <p>Background: Emerging adults with spina bifida have complex health care and developmental care needs. As more children with spina bifida reach adulthood due to improvement in neurosurgical care, transition to adulthood for this population has received increasing attention. However, the experiences during transition for emerging adults with spina bifida in Japan remain unknown. The purpose of this study was to describe the experiences of transition to adulthood for emerging adults with spina bifida in Japan.</p> <p>Methods: Qualitative descriptive design using thematic analysis was chosen to explore the experiences of emerging adults with spina bifida. Eight emerging adults aged between 20 and 29 years living in Japan (37.5% female: 100% living with parents) participated in semi-structured telephone or Skype interviews. The Theory of Emerging Adulthood and the Ecological Model of Secondary Conditions and Adaptation in Spina Bifida influenced the development of the interview guide which addressed transition to adulthood and adult healthcare.</p> <p>Results: Six core themes were identified: (a) struggling, (b) finding the meaning of “being an adult”, (c) learning to implement self-management, (d) health care, (e) processes and challenges in establishing and retaining relationship with friends, and (f) broadening scope of experiences.</p> <p>Conclusions: This study contributed to identification of both challenges and positive aspects in experiences of emerging adults with spina bifida in Japan. Ever present were participants’ experiences of struggling during transition to adulthood, especially when trying to find a job, establishing relationship with friends, and making transition to adult health care. Participants shared their unique perspectives on the meaning of “being an adult” as a person with spina bifida in Japan. Health and social programs assisting emerging adults with spina bifida in achieving milestones for adulthood and transitioning to adult health care in Japanese social context are needed.</p>
Poster 4	<p>The Transition Experiences of Adolescents and Emerging Adults With Spina Bifida: A Synthesis of Literature Published in Japanese Journals <i>Shiho Murayama, PhD; Kathleen J. Sawin, PhD, CPNP-PC, FAAN</i></p> <p>Background: In Japan the prevalence of spina bifida is steadily increasing. As life expectancy of the individuals with spina bifida extends, transition to adulthood has become an important issue. To explore the state of the science on transition experiences of Japanese adolescents and emerging adults with spina bifida and to identify gaps in the current body of literature, a synthesis of research published in Japanese journals was conducted.</p> <p>Methods: A Japanese healthcare research database, Igaku-chuo-zasshi (Japan Medical Abstracts Society), MEDLINE, and CINAHL were searched using the following keywords: “spina bifida” or “myelomeningocele,” “young adult*,” “emerging adult*,” “adolescen*,” and “Japan.” Articles published during the years between 2004 and 2016 as well as historical articles were included for review.</p> <p>Results: The final sample consisted of 22 studies. Five themes were identified: (a) challenges of self-management, (b) health care needs, (c) struggling to achieve social adaptation, (d) threats to mental health, and (e) complexity in quality of life.</p> <p>Conclusions: Previous studies suggested that adolescents and emerging adults with spina bifida had challenges with learning to perform bowel programs independently. Bowel and bladder management were the most common needs. In addition, studies suggested that adolescents and emerging adults with spina bifida had a variety of other needs, such as concerns over education, employment, mental health, and sexual and reproductive health issues in relation to the condition. Adolescents with spina bifida often experienced challenges in learning- and school-related dimensions. More research is needed to develop and provide effective services to meet complex health care needs of the Japanese adolescents and emerging adults with spina bifida during transition.</p>
Group 3: Health Care Transition Outcomes and Readiness Measures/Payment Options	
Poster 1	<p>Challenges of Linking Patient Data across Institutions: A Case Study <i>Laura C. Hart, MD, MPH; Christopher Hanks, MD</i></p> <p>Background: Data sets linking patients’ pediatric and adult medical records could provide another important tool in the study of health care transition to more fully understand the entire transition process – before, during, and after transfer to adult care. Guidance on making such data sets is limited.</p> <p>Methods: The Center for Autism Services and Transition (CAST) is based at The Ohio State University Wexner Medical Center (OSU) and provides transition support and primary care to autistic adolescents and young adults. Many CAST patients received their pediatric care at Nationwide Children’s Hospital (NCH). We sought to link medical record data from both NCH and OSU for CAST patients to better understand their transition to adult care. Our first meeting to discuss this was held with the data management team at NCH in December of 2018.</p>

	<p>Results: We encountered the following barriers: 1. The OSU and NCH Institutional Review Boards (IRBs) had different procedures and consent requirements. 2. The OSU and NCH IRBs were not aware of their differences. 3. It took repeated attempts to ensure that the language of the data use agreements reflected the data transfer needs of the research. As a result of the barriers we encountered, we did not receive final approval to link the data until April 2021.</p> <p>Conclusions: Many technical and regulatory obstacles exist for researchers who would like to link pediatric and adult medical record data from separate institutions to study transition from pediatric to adult care. We recommend that: 1. Researchers interested in linking data sets meet with regulatory personnel at all involved institutions, including the IRB and the staff managing data use and data sharing agreements, prior to initiating such work. 2. Institutions review their IRB procedures and rules with other institutions with whom they frequently collaborate to minimize areas where rules are discrepant.</p>
Poster 2	<p>A Quality Measurement Framework: Pediatric-to-Adult Health Care Transition <i>Annie Schmidt, MPH; Samhita Ilango, MSPH; Peggy McManus, MHS; Patience White, MD, MA</i></p> <p>Background: There has been a dearth of quality measures used in health care transition (HCT) to stimulate quality improvement, define accountability, and align financial incentives. To date, the only consistent form of HCT measurement is from the National Survey of Children's Health, a parental report about HCT preparation. Quality measures need to encompass the complexity of HCT, including transition preparation, transfer, and integration into adult care.</p> <p>Methods: With funding support from the Lucile Packard Foundation for Children's Health, The National Alliance to Advance Adolescent Health (NA) formed a multi-stakeholder advisory group to develop a quality measurement framework with a corresponding set of guiding principles. NA conducted an extensive environmental scan of measurement frameworks and identified transition-related framework domains and guiding principles. The framework was reviewed throughout development by the advisory group.</p> <p>Results: The measurement framework consists of 4 structural domains (health system characteristics, youth/young adult/family (Y/YA/Family) characteristics, community/environmental characteristics, and policy characteristics), 5 process domains (care coordination, clinician HCT activities, continuity of care, Y/YA and family-centered care, Y/YA/Family HCT activities), and 4 outcome domains (clinician experience, patient experience, population health, and utilization/cost of care) that align with the structured HCT process of preparation, transfer of care, and integration into adult care.</p> <p>Conclusion: NA will conduct a thorough review of existing measures pertaining to HCT. Existing measures will be prioritized by criteria identified by the advisory group and organized using the measurement framework. Once existing measures and measure gaps are identified, NA will conduct outreach to key federal and national organizations to encourage HCT quality measure consideration and adoption.</p>
Poster 3	<p>Feasibility and Acceptability of a Cystic Fibrosis Health Care Transition Questionnaire for Adolescents/Young Adults and their Parents <i>Tyra C. Girdwood, BSN, RN; Jennifer L. Goralski, MD; Elisabeth P. Dellon, MD, MPH; Mary H. Palmer, PhD, RNC, FAAN, AGSF; Mary R. Lynn, PhD; Maria E. Ferris, MD, MPH, PhD; Mark. P. Toles, PhD, RN</i> <i>"Feasibility and Acceptability of a Cystic Fibrosis Health Care Transition Questionnaire for Adolescents/Young Adults and their Parents"</i></p> <p>Background: Adolescents and young adults (AYA) with cystic fibrosis (CF) experience challenging pediatric to adult health care transitions (HCT). Few tools are available to assess factors that impact transition readiness. The purpose of this study was to describe the feasibility and acceptability of a new, composite CF-specific measure of HCT among AYA with CF who had not yet completed HCT, and their parents.</p> <p>Methods: Based on the Health Care Transition Research Consortium Model, an online questionnaire was developed and administered through Qualtrics®. The questionnaire included multi-level measures designed to assess aspects of transition readiness. Parents and AYAs (12-21 years old) were recruited by email from a large, pediatric CF care center in North Carolina. Questionnaires were administered to parents first and, then only with permission, to AYAs. We examined response rate - number of respondents/total approached, cooperation rate - number of completed questionnaires/total respondents, questionnaire completion time, proportion of missing items, and relevance of the included measures and ease of questionnaire completion.</p> <p>Results: Eighteen of 98 parents (18%) and 5 of 12 AYAs (42%) responded to the questionnaire. Twelve of 18 parents (67%) and 4 of 5 AYAs (80%) completed the questionnaire. The 12 parents were composed of 11 mothers, all were White, and 4 AYA (2 female, 3 White). Median questionnaire completion times were 41.5 minutes (parents) and 11.5 minutes (AYAs). There were no missing data for 10 parents and 2 AYAs. Completed respondents provided few suggestions for questionnaire design changes and minimal suggestions for change to our included measures. 83% of parents and 100% of AYAs reported the questionnaire was easy to complete.</p> <p>Conclusion: Findings suggest that the composite measure was well received by participants, with most respondents completing it. The low response rate could be contributed to COVID-19 recruitment barriers and lack of understanding of HCT importance.</p>

Poster 4	<p>The Relationship Between Parental Catastrophizing and Perceptions of Healthcare Transition Readiness for Youth with Intellectual and Neurodevelopmental Disabilities <i>Diana M. Cejas, MD, MPH; Rafaela Faria; Trieu-Vi Khuu; Robert Campbell, PhD, MS; Miranda van Tilburg, PhD; Maria E. Ferris, MD, MPH, PhD</i></p> <p>Background: A parent's ability to cope with caregiving stress can affect their child's health, especially during their transition to adulthood. Caregiving stress and maladaptive coping skills, including parental catastrophizing, can be high among parents of youth with intellectual and neurodevelopmental disabilities (IDD). Catastrophizing has been associated with negative health outcomes in certain chronic conditions. In this study, we examine the relationship between parental catastrophizing and healthcare transition for youth with IDD, particularly as it relates to parental perception of their child's healthcare transition readiness.</p> <p>Methods: Parents of youth with IDD attending a therapeutic summer camp completed online surveys. Participants reported data on catastrophizing via the Catastrophization Inventory, data on parenting stress via the Pediatric Inventory for Parents, and transition readiness via the Self-Management and Transition to Adulthood with Rx = Treatment (STARx) Parent Questionnaire. Regression analysis measured relationships between parental catastrophizing, parenting stress, and transition readiness.</p> <p>Results: 86 parents completed the measures. Higher levels of parental catastrophizing were associated with lower STARx readiness assessment scores in specific domains including care planning, and disease self-management. Additionally, parents who reported high levels of catastrophizing were more likely to report depressive symptoms and anxiety along with caregiving stress.</p> <p>Conclusions: This study demonstrates the relationships between parental catastrophizing and perception of transition readiness and suggests that the assessment of catastrophizing may be a useful practice during transition planning.</p>
Poster 5	<p>Value-Based Payment and Performance Options for Advancing Pediatric-to-Adult Transitional Care <i>Peggy McManus, MHS; Patience White, MD, MA; Annie Schmidt, MPH</i></p> <p>Background: Medicaid and commercial payers are dramatically expanding their use of value-based payment (VBP) to strengthen capacity of primary care, expand availability of behavioral health care, address social determinants of health, and improve care coordination. Still, few examples have been implemented for pediatric-to-adult health care transition (HCT). New VBP models offer opportunities for aligning financial incentives with structured HCT processes to improve HCT.</p> <p>Methods: The National Alliance (NA), with funding support from the Lucile Packard Foundation for Children's Health, developed a targeted outreach strategy to encourage payers to become early adopters of HCT VBP. Three commercial payers and five Medicaid agencies were initially identified. NA prepared a brief HCT business case statement and partnered with four parent leaders from Family Voices to strengthen the case. NA contacted senior leaders from each payer group to offer free, short-term TA to design a VBP pilot. NA ended up reaching out to a total of 25 payers and health plans/systems.</p> <p>Results: Six Medicaid payers/plans have committed to designing a pilot; two payers have a commercial product but preferred starting with their Medicaid product. Payment and quality strategies, pilot populations, and participating sites vary in each case. HCT interventions are based on the Six Core Elements, with several payers electing to focus on the transfer period. Payment methods under consideration include P4P if certain HCT measures are met, bundled payment for HCT activities during the year before and after transfer, recognizing relevant CPT codes, and enhanced FFS. Quality measures under review are new HCT structural and outcome measures linked to bonuses. Pilot populations are all YSHCN, with four utilizing primary care practices, and one each utilizing behavioral health and specialty care practices.</p> <p>Conclusions: Through targeted effort, payers/plans are planning VBP HCT pilots. Learnings will be discussed and widely disseminated.</p>
Lunch/Breakout Sessions	
Breakout Session 1	<p>Engaging Refugee Youth living with HIV into Care – A Community-Based Approach <i>Neerav Desai MD; Aima Ahonkhai MD, MPH; Leslie Pierce MPH; DeWayne Parker BSW</i></p> <p>Refugee and immigrant youth make up a substantial portion of young people living with HIV in our Southeastern United States region. In our adolescent clinic alone at Vanderbilt University Medical Center (the largest provider of HIV care in Middle Tennessee), 50% of our clients (Ages 10-20) were born outside of the US. A care model that is prepared to meet diverse cultural needs is critical for ensuring optimal health outcomes for our clients including retention in care, adherence to antiretroviral therapy, and successful transition to adult care. 1. Review our care model which integrates a multidisciplinary team of clinical providers with a social worker, case manager, community health navigator (CHN), and community-based organizations (CBO) which provide comprehensive resources to support refugees and immigrants.</p> <p>2. The community-based model allows our clients to access important resources in a setting that is knowledgeable and respectful of their cultural norms without the stigma of disclosing their HIV status.</p>

	<p>3. We have achieved excellent care outcomes among our youth born outside of the US including 100% retention in care and over 80% adherence to care from August 2020 to April 2021. We will also review some barriers and limitations of this model.</p>
Breakout Session 2	<p>Intersectionality; An Added Complexity for Health Care Transition <i>Rita Nathawad, MD; Chanda Jones, MSW(c); Lindsey Hollingsworth, PA-C; Jasmine Brown, MS; Solanica James, LPN; Rashell Lewis, LPN</i></p> <p>The term, “intersectionality”, was originally coined in 1989, by Professor Kimberle Crenshaw, to depict how race, class, gender, and other individual characteristics “intersect” with one another and overlap, to create different forms of discrimination. For youth and young adults navigating the difficult journey to adulthood, intersectionality adds one more layer of complexity. Despite social identity being a core part of adult development, there has been little exploration in the health care transition literature about intersectionality and its impact on successful movement to adult based health systems. Youth and young adults in society today face numerous inequities and are challenged with multiple forms of discrimination such as racism, sexism, classism, and ableism, to name a few. It is critical that we consider the cumulative impact of these different categories and also recognize that they may give rise to unique multidimensional states of oppression and disparities. This session will introduce participants to the concept of intersectionality and explore our role in partnering with patients and families as they navigate these multiple layers of discrimination. We will use self-reflection activities, case examples and video scenarios to explore these concepts as a group.</p> <ol style="list-style-type: none"> 1. Explore how social identity and intersectionality play a role in transition to adulthood. 2. Describe how discrimination and intersectionality may impact clinical care and widen disparities for youth as they move to adulthood. 3. List culturally aware and unbiased communication strategies to address intersectionality in youth as they transition to adulthood.
Breakout Sessions TBA	<p>Special Interest Groups</p>
<p>Platform Session 3: Readiness/Self-Management/Education</p>	
Presentation 1	<p>Health Care Transition Services for Young Adults: Validation of Its Use in the National Survey of Children’s Health <i>Nancy Cheak-Zamora PhD; Chelsea Deroche, PhD; Mojgan Golzy, PhD; Trevor Mandy, BS</i></p> <p>Background: Access to Health Care Transition (HCT) services have been included in national surveys for nearly 20 years. While dozens of studies have assessed HCT questions in the National Survey of Children with Special Health Care Needs and the revised National Survey of Children’s Health (NSCH), no study has assessed the model fit of the HCT questions or validated the measure. This study utilized NSCH data to develop and validate a comprehensive HCT measure.</p> <p>Methods: We utilized three years of NSCH data (2016-18, n= 42,204) to examine the model fit of nine HCT questions. The new measure’s psychometric properties were then assessed by comparing it to theoretically similar and divergent variables including a System of Care indicator, unmet needs, youth employment, and access to mental health services, dental treatment, and mentorship services.</p> <p>Results: An Exploratory Factor Analysis and item culling resulted in 8 items addressing three subscales. Subscales included Guidance toward Independence, Adequate Clinic Visit, and Plan of Care. Model fit was excellent with an Eigenvalue of 1.07 and 89% variance predicted. Examination of initial reliability and content validity indicated high reliability and validity for the scale and subscales. Criterion validity is being assessed.</p> <p>Conclusion: This study is the first to validate the HCT measure in the NSCH. The validated caregiver-report HCT measure assesses the provider’s use of promotion of independence, quality of clinic visit, and planning for current and future care. This novel measure will be a useful tool in clinics, intervention development, and research for special needs and typically developing populations.</p>
Presentation 2	<p>Psychometric Properties of the Transition Readiness Assessment Questionnaire (TRAQ) in a Youth Mental Health Sample <i>Kristin Cleverly, RN, PhD, CPMHN; Sarah Brennenstuhl PhD; Julia Davies RN MN, PhD(c); Brooke Allemang MSW, RSW, PhD(c)</i></p> <p>Background: Successful transitions from child and youth mental health services into adult mental health services are critical to continuity of care and ensuring youth and their families are not negatively impacted. Assessing readiness to transition has been identified as a core component of mental health transition interventions and support services. However, evidence to support the reliability and validity of transition readiness measures for youth with mental illness is limited. The objective of this study was to assess the psychometric properties of the Transition Readiness Assessment Questionnaire (TRAQ) in a sample of youth receiving outpatient mental health services in Ontario, Canada.</p> <p>Methods: Participants (n=237) of the Longitudinal Youth in Transition Study completed the TRAQ at ages 16-18 years prior to transitioning out of child and youth mental health services. The established five factor structure of the</p>

	<p>scale was tested using Confirmatory Factor Analysis, followed by assessment of internal consistency. Convergent and criterion validity were evaluated by assessing relationships between TRAQ scores and measures of developmental maturity, functioning and emotional awareness, and known-group testing based on age.</p> <p>Results: The mean score for the TRAQ was 3.51 (sd = 0.73). The five-factor structure of the TRAQ provided a good fit to the data. The overall scale had good internal consistency ($\alpha = .88$), as did three out of the five subscales. Hypothesized relationships between the TRAQ scores and related measures were confirmed. Older youth were established to have higher TRAQ scores than their younger peers.</p> <p>Conclusion: The TRAQ appears to be a valid tool for assessing transition readiness among youth with mental illness. This tool could be considered as a measure to evaluate interventions designed to promote transition readiness among youth accessing mental health services.</p>
Presentation 3	<p>A Transition Curriculum That Enhances Rheumatology Fellows' Ability to Integrate Young Adult Patients into Adult Rheumatology Care <i>Rebecca Sadun, MD, PhD; Gary R Maslow, MD, MPH; Richard J Chung, MD; Lisa G Criscione-Schreiber, MD, Med</i></p> <p>Background: Greater than 50% of patients with pediatric chronic illness fail to successfully transfer to adult subspecialty care, resulting in preventable morbidity and mortality. The Six Core Elements have been shown to improve transfer, but the majority of adult physicians are unfamiliar with these steps. This study assessed the ability of a new curriculum to teach adult rheumatology fellows how to help patients with pediatric-onset rheumatic diseases integrate into adult rheumatology care.</p> <p>Methods: In July of 2019, 18 adult rheumatology fellows from 4 institutions received an introductory lecture on helping young adult patients successfully transfer to adult care. Of these 18 fellows, 10 participated in 2 additional 1-hour skills-based workshops on transition and spent a half-day working in a young adult rheumatology clinic and implementing learned transition skills. Two months following this clinic, in February of 2020, all 18 fellows, along with 6 additional fellows who did not receive any training in transition best practices, were assessed with a dedicated objective structured clinical examination (OSCE) transition station. Each fellow also completed a self-assessment of their confidence performing 10 transition skills.</p> <p>Results: Participants in the longitudinal transition curriculum demonstrated a significant increase in confidence in 7/10 transition skills ($p = .001$). On the transition OSCE station, the 10 participants of the full 7-hour curriculum scored higher than the 14 control fellows (no intervention or only the introductory lecture) in 3 skills (providing orientation to adult care, $p = 0.05$; placing the patient in the primary role, $p = 0.01$; assessing self-management skills, $p = 0.001$), with a trend toward higher scores in the remaining two skills. The overall OSCE score was 3.9/5 in the intervention group, compared to 2.7/5 for the control group ($p = 0.0002$).</p> <p>Conclusions: Transition skills can be learned through a combination of skills-based workshops and clinical precepting. Future studies should assess the durability of these skills.</p>
Presentation 4	<p>Sickle Cell Transition Skills Lab: Preliminary Evaluation <i>Jerlym Porter, PhD, MPH; Sheila Anderson, BSN; Kathryn Russell, PhD; Jennifer Longoria, PhD; Fang Wang, MS, Haitao Pan, PhD, Jane S. Hankins, MD, MS</i></p> <p>Background: Disease knowledge and self-management skills can improve transition outcomes. Most transition programs focus on knowledge and lack formal and structured experiential skills learning. To increase self-management skills, we developed the Transition Skills Lab (Skills Lab) program for adolescents with sickle cell disease (SCD). In Skills Lab, participants practice three skills: understanding insurance cards, refilling prescriptions, and scheduling medical appointments. We tested the primary hypothesis that Skills Lab participation would be associated with higher post-participation skill confidence and knowledge compared with pre-participation and higher completion of a first adult visit compared with non-participants.</p> <p>Methods: Participants completed a test-retest confidence measure rating their perception of how well they can do the practiced skills and a skills knowledge test prior to and after completing Skills Lab. Disease knowledge scores at age 14 and age 18 and cognitive functioning were ascertained. Correlations, paired t-tests, Wilcoxon two-sample tests, and chi-square tests were conducted to examine differences between pre-post Skills Lab confidence and skills knowledge scores and associations between Skills Lab confidence and skills knowledge and disease knowledge scores, cognitive functioning, and completion of the first adult visit.</p> <p>Results: From 2017-2019, 53 out of 223 (22%) eligible adolescents with SCD aged 15-18 years completed Skills Lab. Confidence ratings and skills knowledge scores significantly increased from pre to post Skills Lab ($p < 0.001$). Disease knowledge quiz scores at age 14 and 18 and cognitive functioning did not correlate with Skills Lab confidence or skills knowledge ($p > 0.05$). Compared to non-participants, Skills Lab participation was associated with completion of the first adult visit ($p < 0.001$). Post Skills Lab knowledge was associated with completion of the first adult visit ($p = 0.01$).</p> <p>Conclusion: Skills Lab is an effective program for teaching transition skills to youth with SCD and is associated with increased confidence and skills knowledge and completion of first adult visit.</p>
Presentation 5	<p>Development, Feasibility, and Acceptability of an EMR-based Transition Readiness Assessment: A Cerner Adaptation of the UNC Transition Index</p>

	<p><i>Lauren Partain, LCSW; Erin Benekos, NP; Wendy Gray, PhD; Kenneth Grant, MD; Hanae Kim, MHA; Michelle Kennedy, LCSW; Karina Chavez, LCSW; Mark Daniels, MD; Donald Phillips, MD; Lilibeth Torno, MD; Michael Weiss, MD</i></p> <p>Background: In alignment with our vision of creating an EMR-based transition assessment and intervention tool, we present data from our development and implementation of the UNC Transition Index created on the Cerner platform. The transition index will be tested in 4 subspecialty clinics focusing on clinical utility and facilitation of research.</p> <p>Methods: Our prototype of the UNC Transition Index was created in Cerner. Staff in the inflammatory bowel diseases, epilepsy, diabetes, and cancer survivorship clinics will be trained in completion of the form for all youth aged 12+. Feasibility (# of forms completed/# administrations possible) and acceptability (i.e., provider satisfaction) will be explored. Additionally, a design session attended by form “super users” will elicit recommendations for revisions and implementation.</p> <p>Results: Thus far, 2 out of 4 clinics have adopted the UNC Transition Index into routine care, with the final two clinics currently undergoing training on the use of the Cerner-based measure. Our super user design session is scheduled for summer and recommendations for improved clinical utility will be identified and incorporated into future iterations of our Cerner-build. We will also share how clinics with different staffing models have incorporated the UNC Transition Index into clinical care.</p> <p>Conclusion(s): Building a standardized transition readiness assessment into the medical record creates the opportunity for annual tracking of patient’s readiness skill development in alignment with national recommendations. Embedding transition readiness assessment into routine care provides the opportunity to deliver targeted, data-informed intervention, which will be the goal of future development of our program.</p>
Presentation 6	<p>Youth Engagement with Patient Navigator During COVID-19 <i>Zoya Punjwani, MPH; Ken Pfister, MSc; Daniella San Martin-Feeney, MSc; Brooke Allemang, MSW, RSW; Laurel Ryan, MFA; Gina Dimitropoulos, PhD, RSW; Susan Samuel, MD</i></p> <p>Background: Transitioning from pediatric to adult health care is a complex time for youth, and COVID-19 has exacerbated barriers to receiving care. The Transition Navigator Trial (TNT) is a randomized control trial evaluating the effectiveness of a patient navigator (PN) during transition. Understanding how youth engagement evolved during COVID-19 is imperative to address barriers.</p> <p>Methods: A retrospective observational study was conducted for youth aged 16-21, with access to a PN within TNT. Encounters with PN (i.e communication between PN and youth, indicating youth engagement with PN), critical encounters (CE), (i.e. encounters requiring urgent attention) and reasons for CE were observed pre-pandemic and since pandemic onset. CE were categorized by the PN as pertaining to medical condition, mental health or social determinants of health (SDOH).</p> <p>Results: In the last quarter of 2019, 113 patients with access to a PN had 186 encounters; 8.6% of these encounters were CE. In the first quarter of COVID-19, 129 patients with access to a PN had 67 encounters; 8.5% of these encounters were CE. 16.2% of encounters were CE in the third quarter of 2020, 12.5% in the fourth quarter of 2020 and 12.0% in the first quarter of 2021. Pre-pandemic, 72.1% of CE were pertaining to medical conditions, 11.6% were related to mental health and 16.3% were SDOH. Since pandemic onset, 89.3% of CE were related to medical conditions, 0% pertaining to mental health and 10.7% were SDOH.</p> <p>Conclusion: Youth engagement with PN decreased during the pandemic; however, the proportion of CE increased. While preliminary evidence suggests mental health issues among youth have been exacerbated during the pandemic, our findings suggest help-seeking for mental health has decreased. These results may inform clinical practice regarding proactive youth mental health assessments during the pandemic.</p>
Poster Session 2	
Group 1: Continuous Quality Improvement/Program Development/Models of Care	
Poster 1	<p>Transition and the Physician Practice Plan: A Proposal to Provide Motivation to do the Right Thing <i>Ann Modrcin, MD, EMBA; Theresa Hickam, MSW</i></p> <p>Background: Our large freestanding pediatric hospital has a robust Transition Program impacting over 10K adolescents in the past 2 years. However, after securing early adopters we noted a decline in rates of Transition discussions and onboarding uncommitted clinics. Senior leadership confirmed commitment to the program and requested a proposal to include Transition-related activities into the new physician practice plan. Divisions meeting objective expectations will be rewarded with bonuses. The aim of this project is to demonstrate a bonus construct to promote desirable behaviors by physicians and clinics.</p> <p>Methods: Engagement and impact in Transition-related activities can be quantified and documented by individual, team and/or divisional effort. For the first stage of the physician practice plan: a) Baselines of Transition-related activities will be documented for each division; b) Divisions will use existing Transition infrastructure integrated into EMR; c) Division will receive Pre-visit Planning reports to identify eligible patients, and Post-visit reports on successful interventions; d) Divisions with documentation of Transition Interventions for 65% of eligible patients</p>

	<p>meet the bonus requirement; e) Electronic Dashboard breaks down transition activity by Division, Location, and providers, so leaders can target successes and area of concern.</p> <p>Results: As this is a proposal no data is available.</p> <p>Conclusion(s): Our experience with divisions who chose transitions projects for bonus-generating Quality Improvement activities uniformly performed well for the duration of the project, after which time the rates of transition task completion reverted to pre-project levels, with few exceptions. Transition to Adult care is a critical pediatric activity, and the right thing to do. Barriers to doing it consistently in terms of time, resources and effort appear to outweigh the benefits of doing it without additional incentive. By offering a tangible reward for consistent and sustained transition efforts, physician engagement is expected to double in the first year of implementation.</p>
Poster 2	<p>Navigation Hub: A Centralized Support for Transferring Adolescents and Young Adults <i>Courtney Porter MPH, CPHQ Rachel Cuevas, BS; Ellen Iverson MPH; Jesus Escobar; Michele Pointer MS; Janet Chavez; Roberta Williams MD; Jennifer Baird PhD, MPH, MSW, RN, CPN</i></p> <p>Background: Adolescents and young adults (AYA) transitioning from pediatric to adult health care systems face numerous challenges, including lack of logistical support with identifying appropriate adult providers, navigating communication with insurers, and transferring care to the new provider. Pediatric clinicians lack expertise in these systems-coordination skills and dedicated time to provide this level of care coordination.</p> <p>Methods: Within the context of an institution-wide approach to transition support for AYA, we designed and implemented the Navigation Hub. The hub serves as centralized support for navigating insurance and benefits systems and transfer to adult providers. Three case managers meet with patients to identify patient priorities, explore provider availability within the insurer's care network, and assist with transfer-related coordination and establishment of service with benefit programs. Support for an individual patient continues until all transfer-related goals are achieved. To ensure continuous refinement of services offered, we conducted a survey of providers whose patients had accessed the hub.</p> <p>Results: The Navigation Hub was launched in September 2020 with support for 4 subspecialty clinics. An additional 4 clinics were added in January 2021, with the goal of continued expansion until navigation support is available for all patients across the institution. To date, more than 130 patients have received support. Survey responses (n=13) indicated high levels of satisfaction with the ease of referring patients, communication with the case managers, and overall quality of services.</p> <p>Conclusion(s): The Navigation Hub fills a critical gap in the care delivery system for AYA transitioning from pediatric to adult providers by removing transfer-related care coordination activities from pediatric providers to a centralized group with coordination expertise. Ongoing evaluation will help to identify standard processes for this coordination, activities of greatest value, and mechanisms for long-term financial viability.</p>
Poster 3	<p>Developing a co-designed healthcare transition intervention with young people with spinal cord injuries <i>Emily Bray MSW(Q), PhD (candidate)</i></p> <p>Background: While healthcare transition (HCT) interventions are recognised as an important area in paediatric rehabilitation, there has been limited research focusing on young people with spinal cord injuries (SCI). Further, a scoping review did not identify the use of participatory research methods in the design of HCT interventions for young people with SCI even though engagement of individuals with lived experience has been advocated. These gaps provide support for research to focus on HCT interventions that engage young people with lived experience of SCI in service design and improvement. This poster presentation will outline a study in which researchers will do just that, collaborate with young people with SCI and their parents/caregivers to develop, implement and evaluate the feasibility and acceptability of a HCT intervention aimed at supporting young people with SCI during their transition from paediatric to adult healthcare services.</p> <p>Methods: A participatory action research (PAR) approach will inform the co-development, implementation and evaluation of a HCT intervention for young people with SCI. The study includes semi-structured interviews, co-design workshops, focus groups and telephone interviews with 6 young people with SCI aged 14-25 years and 6 parents/caregivers.</p> <p>Results: This study provides valuable insights into young people with SCI and parent/caregivers' experiences of HCT and their needs, some of which include a coordinated and streamlined handover from paediatric to adult healthcare provider and 'just in time' information, such as where to go or who to call for support and advice. As co-researchers the participants are included in the analysis of the interviews and will co-design a prototype HCT intervention which will be implemented and then evaluated for feasibility and acceptability.</p> <p>Conclusions: Addressing the needs and the current gap in services has the potential to improve outcomes such as quality of life, health status and independence for young people with SCI.</p>
Poster 4	<p>Developing a disease-agnostic multidisciplinary transition clinic: A pilot exploration of clinic operations and patient needs and experiences <i>Erin Benekos, MSN, RN, NP-C, CPHON; Lauren Partain, LCSW; Wendy N. Gray, PhD; Michael Weiss, MD</i></p> <p>Background: The Adolescent to Adult Bridge (A2B) transition clinic was created to serve a high-risk subset of patients whose transition needs exceed what can be provided via routine well-child and/or specialty care visits.</p>

	<p>Evaluating the process of creating such a clinic and identifying common patient needs may help to inform future program development within our clinic and at other institutions.</p> <p>Methods: Patients are referred to the A2B clinic by their primary care or subspecialist provider following a structured risk assessment. A2B patients and their families are seen by a nurse practitioner and social worker, who assess the patient's transition readiness, identify unmet medical and psychosocial needs, and link patients with needed services. Patient/parent satisfaction is assessed following each visit to the A2B clinic.</p> <p>Results: To date, 20 patients have been seen in the A2B clinic, with most referrals coming from Neurology. Most patients in the A2B clinic have an intellectual or developmental disability. Common issues identified/addressed include clarifying current and future insurance coverage and accessibility, care coordination for patients transferring to multiple adult specialists, identifying in-network adult providers, and linking patients with developmental disability and mental/behavioral health services. Patient satisfaction data is currently being collected and will be presented.</p> <p>Conclusion(s): Most presenting concerns in the A2B clinic fall within the domain of care coordination. Navigating the transfer process across primary care and multiple subspecialties is a common challenge. Feedback obtained from patient satisfaction surveys will be used to refine services in the A2B clinic and guide future expansion efforts.</p>
Poster 5	<p>Utilizing ATHN Clinical Manager to Develop and Monitor an Evidence-Based Transition Program <i>Beng Fuh, MD; Lora Joyner, MS, PT, PCS; Danielle McCloskey, MPH; Chelsea Rivenbark, MSN, FNP-C; Hillary Weismiller, MPH</i></p> <p>Background: Adolescents with bleeding disorders experience increasing morbidity and mortality as they transition into adulthood. Transition is associated with lapses in health insurance, increased risk of complications, and socioeconomic and psychosocial barriers care. Structured, education-based transition programs improve disease knowledge, self-management, and likelihood of continued follow up with adult healthcare services. At East Carolina University Hemophilia Treatment Center (ECU HTC) , we began leveraging the tools and data available through ATHN Clinical Manager, aiming to increase the number of identified young adults who require transition services, facilitate patient engagement in the transition planning process, and monitor outcomes post-transition</p> <p>Methods: ATHN Clinical Manager was utilized to identify all active HTC patients from ages 12 to 25. Initiation of the transition process was based on age, maturity, and psychosocial factors. Using site-specific inclusion flags, patients were provided transition services within one of three groups: transition education (ages 12-16), transition planning (16-22), and post-transfer education and follow up (18-25). Visit sub-types were created to indicate which services were provided and to indicate updated transition plans.</p> <p>Results: Transition program implementation began in 2019 and remains ongoing. Thus far, we have identified 81 patients in need of transition services and 13 in need of transition-related disease education. A total of 53 patients are currently receiving transition services, representing 65.3% of the identified patients aged 12 to 25. Twenty-two of these patients are in phase one (transition education), 28 patients are in phase two (transition planning), and three are in phase three (post-transfer education and follow up).</p> <p>Conclusion: Our ATHN Clinical Manager transition registry provides an excellent tool for identifying patients and monitoring transition services. Utilization of ATHN Clinical Manager for this purpose has enabled our team to examine data and address clinical, socioeconomic, and psychosocial factors relating to transition.</p>
Poster 6	<p>Modifying Transition Support Programs for Adolescents and Young Adults to Virtual Programming <i>Jodie Neukirch Elliott, LCSW; LaKaya Craig, LCMHCA; Mary Long; Samuel Brotkin, MA; Marlyn Wells; Pamela Dixon; Alison Manning, MD</i></p> <p>Background: Adolescents Transitioning to Leadership and Success (ATLAS) is comprised of several programs that offer in-person support and mentorship for adolescents and young adults (AYA) with chronic conditions or intellectual/developmental disabilities (I/DD) and their parents since 2010. Due to the COVID-19 pandemic, a transition from in-person to virtual programming was implemented and a qualitative improvement study was conducted. All ATLAS programs, including the monthly mentorship meetings, monthly health and wellness meetings, summer camp-conference and annual prom were converted to a virtual format.</p> <p>Methods: 10 AYA participants (ages 12-18) living with a chronic medical condition and their parents were recruited from affiliated ATLAS programs to complete surveys related to preferences for virtual programming. 10 mentor participants (age 18-24) completed focus groups. Following modifications to the program, AYA participants completed satisfaction surveys, and parents completed phone calls with program staff to determine the acceptability and feasibility of the virtual format.</p> <p>Results: Program modifications were made based on participant feedback and were well accepted. Initial attendance for virtual programming was similar to in-person participation. For some programs, attendance decreased over time as participants reported feeling overwhelmed with their overall amount of online activities (including virtual school). Overall, findings revealed that participants and parents were satisfied with the virtual format.</p>

	<p>Conclusions: Virtual programming was both feasible and well accepted by participants. Based on input from program participants, modifications were developed to foster supportive healthcare transition programs for AYAs. Additionally, many AYAs who were previously unable to attend due to distance from the site or health status joined the programs and began to attend. As a result, after in-person programming is safe to resume, we plan to integrate hybrid programming to include both in-person and virtual components.</p>
Poster 7	<p>RN Health Care Transition Champions: Building Self-Efficacy <i>Linda Tirabassi-Mathis PhD RN CPNP CNS; Martha Franco Garcia MSW LCSW</i></p> <p>Background: A lack of confidence in transition education within the context of adolescent centered care, similar to literature reports, was expressed by our frontline clinical nurses in the outpatient specialty clinics. A RN Health Care Transition Champion role was implemented. Fourteen nurse champions served as a resource for their health care teams and in identifying patients requiring transition education. Bandura's Social Learning/Self-Efficacy Theory framed the performance improvement project. The goal was to increase RN self-efficacy and build confidence in addressing important adolescent and young adult (AYA) transition concerns. Targeted transition education was the primary intervention. Volunteer RN champions were incentivized by the clinical advancement program.</p> <p>Methods: Eleven of 14 champions completed the education and surveys. Self-efficacy indicators were adapted from transition readiness survey items. Two phases of transition education were provided. Surveys were conducted as a pre-intervention baseline, at three and six months, and one-year post education.</p> <p>Results: Targeted transition education supported increased RN champion self-efficacy to not only provide direct patient education but also to coordinate the plan of care. Survey results ranged from 8 to a 69 percent change; with a 28% median; three RN champions did not change from their initial high self-efficacy ratings.</p> <p>Conclusion: Designating roles to address specific transition resources was a project strength. Increased self-efficacy increased RN champion knowledge and enhanced their commitment to the imperative of transition.</p>
Poster 8	<p>Giving Youth the Power: Establishment of an Adolescent and Young Adult (AYA) Leadership Research Council <i>Courtney Wells, PhD, MPH, LGSW; Jaxon Abercrombie, BS; Hannah Adams; Kristine Carandang, PhD, OTR/L</i></p> <p>Background: Gaps in healthcare transition services have been widely recognized for decades, yet many of the same practices and poor health outcomes persist today (Willis & McDonagh, 2020). There is a need for a drastic change in approach, away from a narrow, clinician-centric focus and toward a more AYA patient-centered model of care. Making this shift requires the engagement of AYAs in research and leadership activities.</p> <p>Methods: Funded by the Patient-Centered Outcomes Research Institute, we formed a nationwide (U.S.A.) AYA Leadership Research Council consisting of diverse AYAs with autoimmune conditions who will be trained in patient-centered research, pressing adolescent health issues, and leadership skills. Researchers will be able to partner with research-ready AYA Council members to advise, collaborate, and lead portions of their studies. Additionally, the Council will engage their AYA peers in content that disseminates research findings and details ways to become involved in research studies.</p> <p>Results: This presentation will describe the initial implementation of the AYA Leadership Research Council, including the establishment of shared governance guided by the Typology of Youth Participation and Empowerment (Wong, Zimmerman, & Parker, 2010) and principles of community organizing. We will share lessons learned from our efforts to recruit and retain a diverse group of AYAs. We will also share our ongoing training plan to increase Council members' research literacy and delineate our next activities, which will empower the AYAs to utilize their expertise. Finally, we will present preliminary process evaluation findings from the initial 6 months of the council.</p> <p>Conclusion: Ultimately, the goal of the AYA Leadership Research Council is to change research culture by including AYAs in its conversation and providing a platform for their voices. Our model has the ability to produce AYA-centric research teams who are poised to solve long-standing adolescent health issues.</p>
Group 2: Health Provider or Patient/Caregiver Education	
Poster 1	<p>Perspectives of Medical Students Completing a Transitional Care Elective Experience <i>Annamaria Arostegui ; Adam Greenberg NP; Natalie Stollon LSW; Symme Trachtenberg LSW; Christine Chamberlain RN; Dava Szalda MD MSHP</i></p> <p>Background: The Perelman School of Medicine offers students a "Transition from Pediatric to Adult Care" elective. During this elective, students work with an interdisciplinary transition consult service that helps patients with chronic health conditions and/or intellectual disabilities transition from pediatric to adult healthcare. Students also rotate through subspecialty transition clinics (e.g. Cystic Fibrosis, Cerebral Palsy, Sickle Cell, Hemophilia, Spina Bifida etc) and attend transition related lectures.</p> <p>Methods: An open-ended ten question post-elective reflective exercise was given to each student from 2018-2020. Questions included inquiries into students' perceptions of the biggest barriers and most important outcome measures for transition and useful educational content. Reflections were compiled and qualitatively coded.</p>

	<p>Results: Twenty-two students completed the elective, and eighteen completed the post-rotation reflection. In terms of barriers, 61% of students felt that care coordination is largest barrier to an effective transition, and the majority (72%) identified providing this coordination as the most important intervention while 28% cited a comprehensive medical summary as the most important intervention. Half of students (50%) felt that the most important transition outcome measures were quantitative medical outcomes (e.g., health care utilization) and half (50%) felt that the most important measures were psychosocial outcomes (e.g. patient quality of life). Students cited the most useful aspect of the elective was spending time with a transition team. Over half of students (56%) reported that the rotation helped solidify their future career choice and that they would like to specifically incorporate transition into their future careers.</p> <p>Conclusions: Medical students found a two-week elective to be a useful experience in learning more about transitions from pediatric to adult-focused care. After this immersive experience, students were split on what the most pertinent transition outcome measures are. Most students who completed the elective plan to formally incorporate transition into their future careers.</p>
Poster 2	<p>Health Care Transition Planning: A Potpourri of Perspectives from Nurses <i>Cecily L. Betz, PhD, RN, FAAN; Jennifer E. Mannino, PhD, RN; Jennifer A. Disabato, DNP, CPNP-PC, AC; Victoria Marner MSN, BA, RN-BC</i></p> <p>Background: Nurses have important roles as members of the health care transition planning interdisciplinary team. Nursing's scope of practice and framework of care brings a distinctive and complementary approach to this rapidly expanding field in pediatric care. It is therefore relevant to better understand the extent to which pediatric nurses are involved with the provision of HCT services and model development.</p> <p>Methods: Qualitative analysis of an open-ended response item of a national survey of pediatric nurses. A thematic iterative process was used to code data. Three coders separately analyzed responses then met to compare and discuss until a final list of codes was achieved. The codes were further analyzed until themes and subthemes emerged. Throughout the process, disagreements were discussed and resolved until consensus was achieved.</p> <p>Results: A sample of 1814 pediatric nurses and nurse practitioners from two U.S. professional organizations participated in this national survey to gather data on their involvement in health care transition planning. This survey contained 17 items, one of which was an open-ended asking the question: Is there anything else you would like to share about your role with the population of transitioning youth and young adults with chronic illness and/or disability? The analysis of responses provided by 154 nurses is presented. Initial coding resulted in twelve categories of data. Four major themes including four subthemes emerged from analysis of responses: Support the need for transition (subtheme: Nursing involvement); Guidance needed for professional practice (subtheme: Types of guidelines and training); Lack of service linkages to adult providers; and Difficulty letting go (two subthemes: Pediatric providers; Parents).</p> <p>Conclusions: As these findings indicated, there is strong support for the need for HCT services; however, challenges to HCT implementation were identified.</p>
Poster 3	<p>Health Care Transition Planning: Educational Needs of Pediatric Nurses and Nurse Practitioners <i>Jennifer E. Mannino, PhD, RN; Cecily L. Betz, PhD, RN, FAAN; Jennifer A. Disabato, DNP, CPNP-PC, AC; Sharon M. Hudson, PhD; Victoria Marner MSN, BA, RN-BC</i></p> <p>Background: Advances in health care have considerably improved the survival rates of youth and young adults (YYA) with chronic illness and disability. As 90% now enter adulthood, Health Care Transition Planning (HCTP) has emerged as a nursing practice priority. The welcomed advances in health care have created new demands for HCTP knowledge. Identifying the educational needs and making learning accessible is necessary for creating experts in this area.</p> <p>Methods: Mixed method descriptive analysis of survey data and open-ended response items pertaining to educational needs and preferences were extracted from a larger national study exploring the role and the provision of HCTP activities by pediatric nurses and nurse practitioners (n=1814). Previously published findings indicated activities performed by nurses widely reflect the standards of practice for YYA with complex and chronic conditions but are not specifically associated with the transition process.</p> <p>Results: Almost all respondents were certified in their field (93%) and involved in the direct care of patients 14 years and older (94%). The need for HCTP information is warranted. Only 18% reported having specific HCTP training which was received mostly in the form of continuing education units through conference and seminar participation or as part of academic coursework while pursuing an advanced degree. Conversely only a small portion of respondents reported the training was received in their own facility. Educating youth and young adults in self-management skills was identified as the highest ranked HCTP educational priority and a need for information pertaining to specialized populations was indicated.</p> <p>Conclusion: HCTP care advancements necessitate HCTP training and development of nurse-led service efforts to facilitate optimal outcomes for youth and young adults with chronic illness and disability. Making learning more accessible in the workplace by increasing educational opportunities throughout the workday and incentivizing specialized training may contribute to the lifelong learning needs of the nurse and creating experts in HCTP.</p>

Poster 4	<p>The Impact of Provider-Directed Communication Strategies on Engagement with a Pediatric to Adult Transition Program <i>Elizabeth F. Vann MS, RN, AE-C; Virginia C. Urbine BSN, RN, AE-C; Meghan S. Camacho, BA; William C. Anderson III, MD</i></p> <p>Background: Healthcare providers still lack familiarity with the terminology associated with the transition of adolescents and young adults (AYAs) to adult care. Particularly, the concepts of “transition” and “transfer” may be confused and could delay engagement in the transition process, assuming it means the move to adult care. Our objective is to explore how the introduction of transition to pediatric specialty providers caring for patients with asthma impacts their referrals to an asthma-specific transition program.</p> <p>Methods: Children’s Hospital Colorado has established the Asthma Self-Care, Education, and Transition (ASCEnT) Program to assist in the transition of AYAs with asthma to adult care. A retrospective chart review was conducted from 2/1/2020 to 4/30/2021 to evaluate the frequency of referrals to the ASCEnT Program from pediatric providers in Allergy and Pulmonology clinics. Providers were contacted by the ASCEnT asthma care coordinators via EMR message, prior to the clinic visit, for approval to recruit. Messaging was initially billed as “Asthma Transition Planning” focusing on the age-specific core elements of transition and then changed to “Adolescent Adult Asthma Planning” focusing on self-management and education.</p> <p>Results: Two hundred fifty-nine patients were recruited (203 patients from Pulmonology; 56 patients recruited from Allergy). From 04/2020 to 10/2020, there was a 56% provider referral rate utilizing “Asthma Transition Planning” messaging. Following a change in messaging to “Adolescent Adult Asthma Planning” in 11/2020, the provider referral rate increased to 80%. Feedback from providers prior to the language change included unfamiliarity with the program and patients being “too young” to transition.</p> <p>Conclusions: Referrals to an asthma-specific transition program improved when terms such as “adolescent to adult planning” or “transition education” were used over “transition” and “transfer”. When introducing transition planning to providers, we recommend emphasizing the impact of such planning on patient self-management skills and minimizing use of potentially confusing terminology.”</p>
Poster 5	<p>Pediatric Providers’ Educational Needs Regarding Transition from Pediatric to Adult Healthcare <i>Laura Kirkpatrick MD; Eleanor Sharp MD; Ahmed Abdul-al; Andrew McCormick MD; Loreta Matheo MD; Traci M. Kazmerski MD, MS</i></p> <p>Background: Best practice guidelines on the transition of patients from pediatric to adult healthcare recommend beginning transition discussions at the onset of puberty. Prior research in specific subspecialties suggests low rates of adherence to these recommendations in practice.</p> <p>Methods: We distributed an anonymous, online cross-sectional survey of physicians and advanced practice providers (APPs) at a single free-standing children’s hospital using institution listservs to assess attitudes, practices, and preferences regarding education and transition-related interventions. We employed descriptive statistics to analyze the data.</p> <p>Results: To date, 165 providers responded (17% response rate) across 33 pediatric provider groups (including 71% faculty physicians, 11% physicians in fellowship training, and 18% APPs). Respondents were 67% female. Less than half (46%) were confident in their knowledge of the transition process and about a quarter (23%) were satisfied with their team’s transition process. Forty percent report beginning transition discussions at age 18 years old or older, with forty seven percent reporting annual transition discussions. Respondents reported low-to-moderate confidence in transition-related skills (ranging from 14% confidence in discussing power of attorney to 61% confidence in referring to adult providers). Educational topics of greatest interest included legal (71% interest) and financial concerns (69%) in transition, while preferred educational formats included Grand Rounds or lectures (68%) and a webinar with real-time discussion (63%). Identified facilitators to transition included lists of local adult providers for transition (89%), parent/family educational resources (88%), and a medical summary tool built into the electronic health record (85%).</p> <p>Conclusion: Pediatric providers endorse significant gaps in their knowledge related to transition and report suboptimal transition practices. Identified educational strategies and facilitators may serve as targets to improve the transition process in this institution.</p>
Poster 6	<p>Co-designing a digital health intervention with early adolescents with chronic health conditions: Setting the stage for active patient engagement in the transition journey <i>Caitlin Sayegh, PhD; Margeaux Akazawa, MPH; Kate Berman, BA; Rachel Cuevas, BS; Emmy Flores, BA; Luis Morales, BA; Anne Nord, MSN, FNP-C; Courtney Porter, MPH, CPHQ; Emily Reich, PhD; Maurice Tut, MSHCM, MSIS; Roberta Williams, MD; Ellen Iverson, MPH</i></p> <p>Background: Stakeholder interviews with young adults with chronic illness and pediatric and adult healthcare providers highlighted that early adolescence was often a missed opportunity for actively including youth in their healthcare and readying them for transition. Stakeholders described a tendency for early adolescents to feel overlooked, confused, apprehensive, or disengaged in their healthcare. Through a user-centered design process, we identified a digital health intervention concept to enhance independent healthcare skills and prepare youth to</p>

	<p>advocate for their needs and goals. This digital tool would use gamification principles to engage early adolescents in developing transition readiness skills in a fun, unthreatening manner in a format consistent with how they like to use technology.</p> <p>Methods: In partnership with a family advisory board, we will complete iterative co-design and usability testing of the digital tool with a sample of approximately 35 early adolescents (13-to-15 years old) and their caregivers, as well as with 10 healthcare providers. We will use mixed-methods to assess qualitative responses to the tool throughout development, as well as incorporate quantitative measures including the Mobile Health App Usability Questionnaire (Zhao et al., 2019) and Suitability of Materials tool (Doak, Doak, & Root, 1996).</p> <p>Results: Design and usability testing sessions will be complete by September 2021. Results will include qualitative themes describing how early adolescents, caregivers, and healthcare providers view the tool's potential efficacy for promoting transition readiness in early adolescence. In addition, qualitative and quantitative data evaluating the usability, health literacy demands, and cultural appropriateness of the tool will be presented.</p> <p>Conclusion: The results of this study will illuminate how early adolescents, caregivers, and providers believe digital technology can promote more active involvement in health care and jumpstart the development of transition readiness. These data will result in a useable prototype of a digital transition tool for early adolescence.</p>
Poster 7	<p>Distinguishing Reality Versus Perception in Provider-Identified Barriers to Transition from Pediatric to Adult Care <i>William C. Anderson III, MD; Jennifer A. Disabato, DNP, CPNP-PC, AC</i></p> <p>Background: The AAP/AAFP/ACP transition from pediatric to adult healthcare guidelines emphasize partnership between adult and pediatric care providers. However, pediatric providers may be hesitant to transfer patients to an adult setting if they feel it may lead to suboptimal care.</p> <p>Methods: A survey was distributed to pediatric and adult healthcare providers at an academic medical center assessing their attitudes towards perceived barriers to pediatric to adult transition. The survey was distributed to individual primary care and specialty sections with instructions to be completed by a representative, such as section head, clinic medical director, or a transition lead.</p> <p>Results: Twenty-six pediatric providers and 25 adult providers responded to the survey on behalf of their sections. The majority of pediatric care respondents were specialists (77%) while the majority of adult care respondents were primary care providers (56%). Pediatric providers identified a rare disorder requiring disease-specific pediatric care (61.1%), a quality or safety advantage in pediatric care (55.6%), and lack of an adult provider with expertise in this population (55.6%) as the primary barriers to adult care transition. Pediatric providers rated the overall availability of adult providers willing to accept young adult patients (40%) and adult provider knowledge about the disease-specific management (32%) as the top challenges to patient integration into adult care. Conversely, adult providers rated medical complexity (85.7%), comfort level of providers with pediatric onset diseases (72.7%), and quality and safety advantages (57.1%) as rarely or sometimes barriers to a successful transition and integration into adult care.</p> <p>Conclusions: A discrepancy exists between pediatric providers' perception of and adult providers' reported comfort with caring for pediatric-onset conditions, leading to a potentially unnecessary barrier to transferring patients to adult care. This difference between perception and reality emphasizes the need for increased structured, transition-focused communication and education between pediatric and adult healthcare providers.</p>
Group 3: Self-Management	
Poster 1	<p>Peer Coaching to Support Transition from Pediatric to Adult Care for Adolescents and Young Adults with Chronic Conditions: Intervention Dose <i>Mirai Matsuura; McLean D. Pollock, PhD, MSW; Sharron L. Docherty, PhD, PNP, RN, FAAN; Gary Maslow, MD MPH</i></p> <p>Background: Peer-based support interventions have been utilized to support adolescents and young adults (AYAs) with childhood-onset chronic conditions (COCCs) as they transition into adulthood. However, consistent participation in these interventions can be a challenge. As part of a larger study testing the efficacy of a web-based peer coaching intervention to support self-management and patient activation in AYA with COCCs as they transition to adult care, we analyzed early patterns in demographic and clinical factors that influence the intervention dose received.</p> <p>Methods: AYAs, 16-22 years with a COCC (e.g., Lupus, cancer survivor, diabetes) were randomized in a 2:1 ratio to intervention and active control group. Forty participants were included in the analysis. Non-parametric tests were used to explore the demographic and clinical factors associated with the number of calls completed during the first three months of the intervention, during which calls were expected to be conducted weekly.</p> <p>Results: Two-thirds of participants completed at least 8 of the 12 expected calls. Participants of Hispanic/Latino ethnicity completed significantly fewer calls than their non-Hispanic/Latino peers ($p = 0.02$). Participants with parents who did not attend college had significantly fewer coaching calls than those whose parents completed at least some college ($p=0.005$). There was no significant difference in number of calls completed based on whether the participant and coach had matching conditions.</p>

	<p>Conclusions: Understanding the relationships between demographic and clinical characteristics and intervention dose will allow clinicians and researchers to better engage and support those who may face barriers to participation. Contrary to previous studies focusing on peer support within the same condition, matching participants and coaches by condition did not influence the dose of coaching calls received.</p>
Poster 2	<p>A.L.L. Y.O.U. N.E.E.D. I.S. L.O.V.E. Manual on Health Self-management and Patient-reported Outcomes among Low-income Young Adult Mexicans on Chronic Dialysis <i>Juliette Brito, RN, MSc; Elba Medina, MD, MSc; Mara Medeiros, MD, PhD; Guillermo Cantú-Quintanilla, MD, PhD; Luis Eduardo Morales Buenrostro, MD, PhD; María E. Diaz-González de Ferris, MD, MPH, PhD; Rafael Valdez-Ortiz, MD, PhD</i></p> <p>Background: Chronic kidney disease (CKD) and end-stage renal disease (ESRD) have complex medical, dietary and fluid regimes. Incident young adult hemodialysis patients must learn about their disease and how to manage it. The Spanish version of the CKD/ESRD self-management syllabus called A.L.L. Y.O.U. N.E.E.D. I.S. L.O.V.E. is a low-literacy tool that needs to be validated and correlated to patients' disease knowledge/self-management, health-related quality of life (HRQoL) and biopsychosocial environment of young adults.</p> <p>Methods: A Quasi-experimental study was conducted among incident hemodialysis young adult patients at the Hospital General de México. The translated and back-translated Spanish version of the A.L.L. Y.O.U. N.E.E.D. I.S. L.O.V.E syllabus was implemented in 6 individual weekly sessions. Changes in knowledge/self-management skills (STARx questionnaire and TRxANSITION Index) and HRQoL were measured.</p> <p>Results: We enrolled 17 patients (77% men) with a mean age of 24.1 ± 3.4 years. A significant difference was observed in the knowledge/self-management pre- and post-scores (p <0.05), with a difference of 6.76 (95% CI 11.43 - 2.09) based on the STARx questionnaire and 2.788 (95% CI 3.40 - 2.16) on the TRxANSITION Index. After the educational intervention, changes in the HRQoL were detected in the "Burden of disease", "Effects of kidney disease" and "Satisfaction with health personnel" (p <0.05).</p> <p>Conclusions: The Spanish version of A.L.L. Y.O.U. N.E.E.D. I.S. L.O.V.E syllabus intervention demonstrated early efficacy as it improved the disease knowledge/self-management and HRQoL scores. Follow-up should be extended to assess possible changes in clinical outcomes and indicators of adherence to treatment in dialysis patients.</p>
Poster 3	<p>The Utility of Self-Determination Theory to Predict Health Self-Management Behaviors Among Adolescents and Emerging Adults with Special Healthcare Needs Who are Transitioning to Adult-based Care <i>Cassandra Enzler, MPH; Albert Hergenroeder, MD; Christine Markham, PhD; Constance Wiemann, PhD</i></p> <p>Background: Successful transition from pediatric to adult-based care for adolescents and emerging adults with special health care needs (AEASHCN) requires development of health self-management skills such as medication adherence, scheduling appointments, and refilling prescriptions. Preliminary research on AEASHCN supports the utility of Self-Determination Theory (SDT) to predict and understand self-management behaviors in cross-sectional and short-term observational studies. The purpose of this study is to determine whether SDT constructs predict self-management behaviors in AEASHCN who are preparing to or have transitioned to adult-based care.</p> <p>Methods: Participants were part of a larger AEASHCN cohort aged 17-22 years recruited from the Gastroenterology, Renal, and Rheumatology services at a large children's hospital between November 2017 and December 2018 to participate in a self-management intervention. They completed assessments at baseline, 3-, 6-, and 9-months post-intervention. SDT constructs of autonomy (autonomous and controlled motivation), competence (parent activation), and relatedness (parent and provider autonomy support) measured at 9-month follow-up assessment were used to predict health self-management behaviors (Readiness to Transition Questionnaire) an average of 17.0 ± 4.1 months later. Data were analyzed using linear regression with simultaneous entry of SDT constructs and demographic variables.</p> <p>Results: Participants were 67.9% female, 38.3% Hispanic, 24.7% African-American, 65.4% privately insured, and 72.8% had already transitioned to adult-based care. In the final model, competence (p=0.007), parent relatedness (p=0.001), gender (p=0.016), race (p=0.029), and ethnicity (p=0.011) predicted health self-management (R square=0.366, p=0.000). Autonomy (autonomous and controlled motivation), provider relatedness, insurance status, age, health-related quality-of-life, and transition status were not associated with health self-management in the multivariate model.</p> <p>Conclusions: The SDT constructs of competence and parent relatedness were associated with higher health self-management behaviors. These findings provide a framework for intervention development to improve AEASHCNs' self-management skills.</p>
Poster 4	<p>Factors Associated with Adolescents' Self-Efficacy in Meeting with Their Provider Alone <i>Blanca Sanchez-Fournier, BA; Cassandra Enzler, MPH; Constance Wiemann, PhD; Mary Majumder, JD; Beth H Garland, PhD; Albert C Hergenroeder, MD</i></p> <p>Background: Adolescents with special healthcare needs (ASHCN) preparing to transition to adult-based care must be able to independently discuss their care with providers. Opportunities to practice this behavior should occur in pediatric care, yet fewer than 50% of ASHCN meet with their pediatric providers alone. This study</p>

	<p>identified factors associated with self-efficacy to meet with a provider alone among ASHCN preparing for healthcare transition. Self-Determination Theory (SDT) guided selection of possible factors.</p> <p>Methods: Eighty-three 18-year-olds with renal (n=19), gastrointestinal (n=20), rheumatologic (n=22) and neurologic (n=22) diseases completed a one-time assessment to measure their self-efficacy in meeting with a healthcare provider without a parent/guardian. Questions assessed perceived self-efficacy in meeting with the provider alone (6-item scale, Cronbach alpha=.91); perceived importance of being interviewed alone (scale of 1-10); whether they met with their provider alone in the past 12 months (yes, no/not sure); perceived competence in healthcare self-management (Patient Activation Measure); and SDT constructs of healthcare autonomy and support for health care autonomy from parents and providers. Linear regression (two steps) was used.</p> <p>Results: Participants were 54% female, 13% African-American, 49% Hispanic, and 53% publicly insured. Females reported higher self-efficacy to meet with provider alone than males (5.1±0.8 vs 4.6±1.1, p=0.031). After controlling for gender, competence (p=0.004), having met with the provider alone (p=0.024), provider support for autonomy (p=0.025), and healthcare autonomy (p=0.052) were associated with self-efficacy in meeting with provider alone (R-square=.370, F-change=11.27, p<0.001). Perceived importance of meeting with provider and perceived parent autonomy support did not remain in the multivariate model.</p> <p>Conclusion(s): We have identified four factors that independently contribute to ASHCN self-efficacy to meet with their provider alone and provide a framework for the development of interventions to promote self-efficacy while still in pediatric care. Opportunities to meet with providers alone to develop and practice these skills are needed.</p>
Poster 5	<p>Factors Associated with Patient Activation Among Adolescents and Emerging Adults with Chronic Health Conditions <i>CassandraENZler, MPH; Kathleen Sawin, PhD, RN, FAAN; Albert Hergenroeder, MD; Cortney Zimmerman, PhD; Beth Garland, PhD; Leah Lomonte, MA; Jean Raphael, MD, MPH; Constance Wiemann, PhD</i></p> <p>Background: Adolescents with special healthcare needs (ASHCN) preparing to transition to adult-based care must be able to independently discuss their care with providers. Opportunities to practice this behavior should occur in pediatric care, yet fewer than 50% of ASHCN meet with their pediatric providers alone. This study identified factors associated with self-efficacy to meet with a provider alone among ASHCN preparing for healthcare transition. Self-Determination Theory (SDT) guided selection of possible factors.</p> <p>Methods: Eighty-three 18-year-olds with renal (n=19), gastrointestinal (n=20), rheumatologic (n=22) and neurologic (n=22) diseases completed a one-time assessment to measure their self-efficacy in meeting with a healthcare provider without a parent/guardian. Questions assessed perceived self-efficacy in meeting with the provider alone (6-item scale, Cronbach alpha=.91); perceived importance of being interviewed alone (scale of 1-10); whether they met with their provider alone in the past 12 months (yes, no/not sure); perceived competence in healthcare self-management (Patient Activation Measure); and SDT constructs of healthcare autonomy and support for health care autonomy from parents and providers. Linear regression (two steps) was used.</p> <p>Results: Participants were 54% female, 13% African-American, 49% Hispanic, and 53% publicly insured. Females reported higher self-efficacy to meet with provider alone than males (5.1±0.8 vs 4.6±1.1, p=0.031). After controlling for gender, competence (p=0.004), having met with the provider alone (p=0.024), provider support for autonomy (p=0.025), and healthcare autonomy (p=0.052) were associated with self-efficacy in meeting with provider alone (R-square=.370, F-change=11.27, p<0.001). Perceived importance of meeting with provider and perceived parent autonomy support did not remain in the multivariate model.</p> <p>Conclusion(s): We have identified four factors that independently contribute to ASHCN self-efficacy to meet with their provider alone and provide a framework for the development of interventions to promote self-efficacy while still in pediatric care. Opportunities to meet with providers alone to develop and practice these skills are needed.</p>
Poster 6	<p>Implementing a Virtual Workshop to Improve Transition Navigation Skills in Adolescents and Young Adults with Sickle Cell Disease: A Quality Improvement Study <i>Zelyn Lee, BSc; James Bradley, MOT, OT Reg (Ont); Melina Cheong, MN, NP</i></p> <p>Background: The transfer from pediatric to adult care presents a significant challenge for adolescents and young adults (AYA) with sickle cell disease (SCD)^{1,2,3}. Disease self-management skills have been recognized as a mediator of poor health outcomes^{4,5,6,7}, but transition-related skills such as scheduling appointments and understanding the shift in health care responsibilities remain under taught in transition programs^{8,9,10}. The purpose of this quality improvement (QI) study was to understand the areas of disease self-management that AYA patients felt underprepared for, and assess whether a single virtual workshop (VW) addressing the top disease self-management skills can help patients feel more prepared for transition.</p> <p>Methods: Three cycles of the Plan-Do-Study-Act (PDSA) model were implemented in a tertiary outpatient clinic. In PDSA cycle one, 39 AYA patients (aged 15-18) were surveyed during regular clinic visits to identify their priorities regarding disease self-management skills. PDSA cycle two involved the creation, implementation, and evaluation of a VW based on the survey feedback, while PDSA cycle 3 involved the revision and repeated administration of the VW. In total, 9 AYAs (age 17-19) attended a single, one-hour long VW across two groups. An electronic patient survey was administered immediately after each session.</p>

	<p>Results: Navigating the adult care system' was the top self-management skill that AYA patients felt like they needed more support with during PDSA cycle one. Majority of patients (78%) reported that the VW was excellent, with appointment management being the most useful topic discussed. Participants also reported feeling more confident (78%) and aware (78%) of how to navigate adult care.</p> <p>Conclusion: This QI study showed that a single VW on transition-related skills was well received by AYA patients with SCD. Future steps should include repeated administrations of the group to continue tailoring the content and empower AYA patients with SCD with the necessary skills to transition to adult care.</p>
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Wrap Up