

Healthcare Transition From Pediatric to Adult Care:

Implementation of a Readiness Assessment Tool

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Date of Submission: May 8, 2020

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Abstract

Purpose of Project: The purpose of this quality improvement pilot project was to introduce healthcare transition (HCT) and readiness assessment in a robust pediatric gastroenterology practice housed in a large pediatric subspecialty center and establish and assess workflow for standardized routine healthcare transition (HCT) readiness using the *Transition Readiness Assessment Questionnaire 5.0* (TRAQ/TRAQ-C). Furthermore, the project was designed to assess screening results to make specialty-, diagnosis-, and/or Center-specific screening recommendations using the findings to establish a plan for sustainability within the department and expand screening to the larger subspecialty center. **Methodology:** This project used a convenience sample of patients and their parents/caregivers to implement the TRAQ/TRAQ-C, who presented for a return medical visit to pediatric gastroenterology over a one-month time frame. **Results:** Overall, the workflow was effective. However, collectively the project was labor-intensive and modifications will need to be made to ensure sustainability. There was a TRAQ return rate of 84% however, provider review of the tool fell short at 21.4%. Patients who presented to the visit without a parent scored higher overall on the TRAQ than their counterparts who came with a parent. In addition, the TRAQ-C scores of parent's perceptions of readiness were significantly higher overall ($p < 0.01$) than the TRAQ scores of the patients' assessment of readiness. **Implications for Practice:** Barriers to implementation with provider review exist within this system that includes knowledge of HCT, provider perception of HCT, and perceived time for clinicians to review the completed assessment tool within the allotted timeframe for follow up visits. Additionally, patients demonstrated a deficiency in self-management skills needed for the transition to adult healthcare as measured by the TRAQ tool. Recommendations for sustainability and future projects include: (a) more robust education regarding HCT for

Center providers, parent/caregivers, and staff, (b) introduction of the tool with minor revisions to workflow within motivated Center subspecialties, (c) addition of a HCT facilitator to the Center, and (d) integration of a HCT to the electronic medical record for ongoing HCT surveillance and billing.

Keywords: transition to adult care, healthcare transition, pediatric transition to adult, readiness assessment, readiness tool, transition readiness assessment

Healthcare Transition From Pediatric to Adult Care: Implementation of a Readiness Assessment Tool

In the United States, children with chronic health conditions or special needs face multiple challenges, especially in healthcare and healthcare delivery systems (Perrin, 2002). Evidence suggests the transition from pediatric to adult care presents health risks that can be mitigated with the implementation of a structured healthcare transition (HCT) plan to facilitate successful transition (GotTransition, 2014-2019; Sabbagh et al., 2018). The importance of HCT is now well-recognized as one of the federally funded healthcare initiatives associated with adolescence to promote healthy outcomes. Successful transition to adult care promotes healthy development and psychosocial security and safety (Kim & Ye, 2019). According to the consensus statement from the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians (ACP), and Transitions Report Authoring Group (2011), HCT is vital to ensure patients receive both medically and developmentally appropriate healthcare. Federal and state agencies, as well as professional organizations, are beginning to address this problem through various platforms in terms of initiatives, provider reimbursement, and guidelines for structured transition planning (Camfield et al., 2019; GotTransition, 2014-2019). Despite available resources and evidenced-based tools, providers, and healthcare organizations fail to offer structured HCT planning for adolescents and young adults (White et al., 2018).

Barriers that impede or delay HCT result in a greater percentage of young adults who: (a) continue to receive care from their pediatric-trained healthcare provider that is beyond their scope of practice, (b) lose health insurance, and (c) fail to receive care in either the pediatric or adult setting (Callahan et al., 2001; Fortuna et al., 2012; Reiss et al., 2005; Suris, 1995).

Challenges regarding HCT are especially heightened among specialty providers and parents of children and youth with special healthcare needs (CYSHCN). This unique pediatric subpopulation is defined as individuals from birth to 18 years of age who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children in general (McPherson et al., 1998). Moving from pediatric- to adult-centered care is challenging for typical adolescents but especially complex for pediatric and adult providers, CYSHCN, and their parents/caregivers (Gray, Shaefer et al., 2018). Children diagnosed with chronic illness early in life usually require more frequent healthcare visits to multiple providers. Strong bonded relationships form over time between the providers and their patients and families, often through periods of critical health and major life events (Gray, Shaefer et al., 2018). As this population ages through the stages of adolescence to young adults, needs change that impact physical, intellectual, social, and emotional development (AAP, 2012). As such, CYSHCN are a vulnerable population and one for whom clinicians face many challenges in providing optimal healthcare (McManus et al., 2013).

It is estimated more than 90% of CYSHCN are expected to survive into adulthood and will require HCT (Gleason et al., 2009; Pai & Schwartz, 2011). Evidence suggests patients who receive a structured approach to HCT report better outcomes in terms of quality of life, medication adherence, and self-efficacy (Gabriel et al., 2017) whereas a lack of or poor transition leads to gaps in care and poorer health outcomes (Vaks et al., 2016).

To better understand the significance of HCT, it is necessary to understand key concepts that arise from patients, parents/caregivers, healthcare providers, and healthcare delivery systems. Such concepts include: (a) varied range between healthcare systems and providers to

which HCT takes place, (b) complexity of the transition process, and length of time needed for planning, (c) readiness and self-management skills on the part of the patient, (d) long-standing provider-patient/parent relationships, and (e) system healthcare barriers including insurance coverage, adult provider availability, and lack of educated support staff (White & Cooley, 2018). Additionally, knowledge surrounding the benefits of successful HCT for not only the patient, but our society is fundamental. Given the vast nature of this issue, this project focused on the implementation and use of a HCT readiness tool associated with appropriate preparation and understanding of barriers to timely and successful transition for children and adolescents receiving care in a large pediatric gastroenterology practice.

Background and Significance

In the United States, there are almost 15 million CYSHCN, and approximately 28.2% of households have one or more child who meet these criteria (Health Resources and Services Administration [HRSA], Maternal and Child Health Bureau [MCHB], 2018). Children with special health care needs are costly to the family, society, and healthcare system (Maeng et al., 2017; McPherson et al., 1998; Wafa & Nakhla, 2015). One study indicated CYSHCN had health expenditures three times greater when compared with other children (Vaks et al., 2016). Loss of health benefits due to “aging out” and re-evaluation of Supplemental Security Income of CYSHCN once deemed eligible are now required to re-apply for such services (Wilkschke, 2016). Thus, gaps in care occur due to these legalities (Kaiser Health News, 2016; Social Security Administration, 2017; Wilkschke, 2016). Developments in research and treatment options have extended the life of children living with chronic disease into adulthood (Ferrarese et al., 2016). As such, there is a great need to establish, implement, and evaluate a structured HCT plan (GotTransition, 2014-2019), especially for this at-risk population (White & Cooley, 2018).

The literature suggests patients who receive transition support demonstrate improved care delivery and increased patient health and well-being (McManus et al., 2013; Schütz et al., 2019). Healthcare transition is not a “one-off event” but rather, a structured process (Aldiss et al., 2015) and healthcare providers must plan, collaborate, assess, and provide education to patients and their families several years prior to the transfer to adult care (McPherson et al., 1998). Additionally, if transitions are not successful, CYSHCN are at greater risk for poor health outcomes as adults (Okumura et al., 2013).

Definition of Children and Youth With Special Healthcare Needs

McPherson et al. (1998) defined CYSHCS as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (p.138). This definition is also used by the Maternal and Child Health Bureau (MCHB), the federal agency charged with creating a system of care, optimizing health and quality of life for children in the United States.

Definition of Healthcare Transition

Healthcare transition is defined by Blum et al. (1993) as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (p. 570). Other researchers have built upon this definition to define the transition of care as a process, with steps to ensure continuity of care between two locations or two levels within the same location (Coleman & Boulton, 2003). In either case, the process requires baseline and ongoing assessment of readiness on the part of pediatric and adult providers as well as the patient and family (White & Cooley, 2018).

Genesis of Healthcare Transition

Healthcare transition started in the late 1980s with a “call to action” directive from Surgeon General C. Everett Koop (Office of the Surgeon General, 1987) who implored the nation to vow their commitment to all children and families with special healthcare needs. The 1987 campaign charged HRSA, MCHB, and AAP to develop and lead initiatives in facilitating comprehensive care strategies to mitigate the challenges and obstacles that accompany CYSHCN and their families (Office of the Surgeon General, 1987). Since that time, much research has focused on HCT. Within the last decade, federal care initiative efforts stemming from the MCHB have focused on six outcomes tied to National Performance Measures. The sixth measure of these efforts emphasizes the transition of CYSHCN to adult healthcare services.

Overarching goals of the MCHB are to promote and improve the physical and mental health, safety, and well-being of women and children, and discover how each of these efforts works to achieve successful outcomes for women and children through federally supported initiatives (HRSA, 2018). Within the MCHB Title V Grant Block services, a more specific goal is to increase the number of children with and without special healthcare needs who receive services necessary to transition to adult care (HRSA, 2018). The Association of Maternal and Child Health Programs (AMCHP) and National Maternal and Child Health Initiatives (NMCHI) were charged to develop formal structure and process standards for systems of care serving CYSHCN (Association of Maternal and Child Health Programs [AMCHP], 2017). Two key components gleaned from this white paper include forming standards of care for existing national frameworks for CYSHCN, which focus on system elements rather than disease-specific issues (AMCHP & NMCHI, 2017). Therefore, the foci of pediatric to adult HCT must be on securing structure and processes to help CYSHCN and their parents/caregivers: (a) understand

the condition, (b) traverse the system, (c) maximize health management, and (d) ensure an appropriate transition from pediatric to adult care (AMCHP, 2017).

GotTransition/Six Core Elements for HCT 2.0

Through a cooperative agreement between MCHB and The National Alliance to Advance Adolescent Health, GotTransition/Center for Health Care Transition Improvement works to improve the transition of youth and young adults (particularly those with special health care needs) from pediatric to adult health care by applying new and innovative strategies (GotTransition, 2014-2019). For more than two decades, multiple professional organizations, consensus groups, federal administrations, and stakeholders such as HRSA/MCHB, AMCHB, NMCHI, Lucille Packard Foundation, AAP, AACP, AAFP, and Institute for Healthcare Improvement have tried to address this growing concern (White & Cooley, 2018). Increasing numbers of adolescents and young adults with chronic conditions prompted the Institute of Medicine and National Research Council report (2014) to recognize and prioritize transition from pediatric to adult healthcare as key to improving the health of young adults (IOM, 2014). Among the many recommendations specific to health care organizations and providers, is one that addresses the need for a coordinated process for pediatric to adult HCT (IOM, 2014). Interestingly, the 2014 report identified three key findings in terms of adolescent health, one that care is disconnected, and unstructured, developmental needs are inadequately addressed, and access to evidence-based initiatives are limited (IOM, 2014). This report has served as a guideline for recommendations set forth by Health and Human Services Administration, Centers for Medicare and Medicaid, MCHB, and other federally funded organizations to create initiatives to address this problem (Lu et al., 2015). As such, stakeholders such as the AAP, ACP, AAFP, and The National Alliance to Advance Adolescent Health with the support of the MCHB

developed a structured clinical approach to implement these initiatives. The Six Core Elements were adapted in 2014 as a guide for clinicians to promote the successful transition of youth to adult care services (AMCHP, 2017).

Six Core Elements of Transition 2.0

Funded by HRSA/MCHB, The National Alliance to Improve Adolescent Health together with the Transitions Clinical Report Authoring Group developed a structured clinical approach with sample tools termed “*The Six Core Elements of Health Care Transition 2.0*” (Core Elements) GotTransition, 2014-2019). The Core Elements offers providers a structured process and sample tools to facilitate integration into practice (GotTransition, 2014-2019). The literature recommends introducing elements of HCT to adolescents and their parents/caregivers as young as 12 years, providing a lead time of 8-10 years for the preparation of actual transfer, which can occur anywhere between the ages of 18-22 years depending upon readiness. Collaboration and consensus among providers, patients, healthcare delivery systems, stakeholders, professional organizations, and federally regulated agencies on both state and federal levels are essential to facilitate success. Elements of the HCT process were piloted with methodologies developed by the Institute of Healthcare Improvement, and preliminary research demonstrated the effectiveness of applying the Core Elements in clinical practice (McManus et al., 2015) to ensure successful HCT (White et al., 2018). A summary of the Six Core Elements of Healthcare Transition 2.0 is provided in Table 1. A timeline of the Six Core Elements with respect to age is provided in Figure 1.

In 2018, an updated clinical report for the process of adolescent to adult HCT delivered several new recommendations based on more recent literature. The Core Elements were revised and packaged for healthcare providers with customizable tools for process development and

implementation in practices and healthcare organizations across the country (White & Cooley, 2018).

Benefits of Healthcare Transition

Multiple elements of the HCT process have been studied and evaluated in both children with and without chronic health conditions. The literature repeatedly demonstrates positive health outcomes for patients who receive a structured process and an appropriate HCT plan (Sabbagh et al., 2018). In 2017, Gabriel et al. published a systematic review of 43 studies between 1995 and 2016 that met inclusion criteria. Results showed two-thirds of the studies demonstrated positive health outcomes with structured HCT. The most cited outcome improvements including adherence to care, improved perceived health status, quality of life, and self-care skills. Improvements in service included attendance at adult visits, decreased time frame between the last pediatric visit and first adult visit, and decreased hospitalizations. Cost considerations and factors pertaining to mental health were limitations to this review. Similarly, a longitudinal study over four years in patients with inflammatory bowel disease, Schütz et al. (2019) found patients who received transition services had fewer intestinal complications (21% in the transition group versus 64% in the transfer group). Additionally, since the publication of this systematic review, Maeng et al. (2017) correlated a coordinated process of HCT to reduce healthcare system costs as it relates to emergency room visits and hospitalizations.

Assessment of Transition Readiness

A key element of HCT is the assessment of patient and parent/caregiver transition readiness (GotTransition, 2014-2019). This assessment is essential in guiding providers toward specific constructs that may require reinforcement and/or support (Crawford et al., 2019). A readiness assessment can lead providers to identify potential skill, knowledge, or psychosocial

gaps (e.g., health literacy, self-care management, and health care delivery) that must be addressed to facilitate successful transition (Sawicki et al., 2014). Initial assessment for care plan development, goal setting, and periodic reassessment to measure progress toward independence are necessary. The most recent literature states readiness assessment using a standardized tool is required for coding and billing of transitional care management (GotTransition, 2014-2019). Studies have shown provider assessments alone are not accurate in determining patient readiness (Gabriel et al., 2017; White & Cooley, 2018). If patients fail to attain certain skills and autonomy, success in the adult care setting can be precarious (Steinway et al., 2017). Therefore, assessment of readiness is largely based upon whether the patient can autonomously meet their needs.

In cases of cognitive impairment, readiness assessment relies on the skill level of the parent or legal guardian. In most situations, the parent or legal guardian does have autonomy and mastery of certain management skills. However, issues can arise when children become adults, and parents become either their health proxy or legal guardian. New legislation is underway to offer alternatives such as shared decision making for parents with disabled children (Wilschke, 2016).

Transition Readiness Assessment Questionnaire (TRAQ)

Readiness assessment must be implemented using tools with sound psychometric properties (Cohen et al., 2015). Multiple readiness assessment tools have been evaluated for reliability and validity (see Table 2). Despite tool development, there is a paucity of literature regarding the use and validation of these tools within and amongst specialties. Additionally, the

parent/caregiver perspective of their child's readiness is equally important. Many tools, however, are not designed to obtain parental/caregiver views.

The Transition Readiness Assessment Questionnaire (TRAQ) is a 20-item Likert scale self-assessment measure based on the Stages of Change Model (Wood et al., 2014). The tool estimates adolescent readiness to self-manage five skill domains, including: (a) medication management, (b) appointment adherence, (c) tracking health issues, (d) talking with providers, and (e) managing daily activities (Wood et al., 2014). The Likert scale responses are scored one to five as follows: (1) *No, I do not know how*, (2) *No, but I want to learn*, (3) *No, but I am learning to do this*, (4) *Yes, I have started doing this* and (5) *Yes, I always do this when I need to* (Wood et al., 2014). Of the available tools, the TRAQ has undergone the most robust psychometric testing and as such, is the most widely used (Schwartz et al., 2014). The overall Cronbach's alpha for the TRAQ 20-item self-assessment is 0.94 (Wood et al., 2014). The tool is applicable across multiple sub-specialties and is appropriate in diverse populations (Jensen et al., 2017; Wood et al., 2014). The tool has been translated into Spanish and French for broader use and made available with an Excel datasheet at <https://www.etsu.edu/com/pediatrics/traq/>. The TRAQ tool is in Appendix A (English), B (Spanish), and C (French) and easily adaptable for parental assessment of their child's skill level since the same form is completed by both the patient and/or parent/guardian. To date, however, the TRAQ has not been validated for use in this capacity (Wood et al., 2014).

Needs Assessment

As previously discussed, there are national initiatives focused on improving HCT for young adults, especially CYSHCN. National performance measure 12 focuses on improving the provision and access of transition services to adolescents ages 12 to 17. More recent surveys

(Child and Adolescent Health Measurement Initiative [CAHMI], 2016-2017) have identified New Jersey as falling behind the national average of 13.8% versus 16.7% of CYSHCN who have received services necessary for HCT (CAHMI, 2016-2017). This percentage increased minimally for the 2017-2018 year however, New Jersey continued to fall short of the national average 17.9% versus 18.9% of adolescents who received services related to HCT (CAHMI, 2017-2018). Efforts were taken to mitigate these shortcomings by prioritizing eight challenges related to maternal and child health under the Title V Grant. The only initiatives that could be tied to addressing national performance measure 12 are the percent of children registered to the Birth Defects and Autism Reporting System (BARDS) and the age of autism diagnosis (HRSA & MCHB, 2020). Although New Jersey has introduced several programs to improve specific aspects of adolescent health such as teen pregnancy and drug prevention, there are currently no formal policies or initiatives to implement any of the Six Core Elements of HCT into clinical practice (HRSA & MCHB, 2019).

Project Site

The setting for this project was a large pediatric ambulatory care center (Center) serving pediatric patients who require healthcare from ten types of sub-specialists in an urban setting in central New Jersey. This Center has been a long-time recipient of a tertiary care grant that specifically includes goals to ensure a safe, successful, and timely transition to adult care.

Although HCT is a key feature of the grant, informal assessment of Center providers across disciplines revealed three sub-specialties utilize HCT tools that target a specific population. These include the R.I.S.E. (responsibility, independence, self-care, education) program for adolescents with cystic fibrosis (Cystic Fibrosis Transition Advisory Council, 2019), a non-validated readiness assessment tool for adolescents with HIV, and a non-specific program

for children with diabetes. Alternatively, other disciplines expressed they transition patients informally using no specific system or process. Regardless of the method, a query of the electronic medical record (EMR) revealed the Center cares for many individuals above the age of 21 which suggest patients are not transitioned in a timely manner. Additionally, though the pediatric pulmonology center utilizes a formal program that addresses HCT for adolescents with cystic fibrosis, providers admitted integration of the tool is less than ideal, and they, too, encounter HCT barriers. Providers informally reported they care for patients as old as 31 years of age.

Baseline Data

A de-identified query of information was obtained on March 30, 2019, through the Center's EMR (Centricity) from January 1, 2018, through December 31, 2018. During that time, the Center served approximately 10,000 patients for a combination of acute/short term and chronic health care visits. To capture the number of adolescents and young adults with chronic conditions, a report of all patients who had at least two return patient visits to this Center over the one-year timeframe with any of the ten sub-specialty providers were included. Of the 10,000 patients, 1895 patients were ≥ 14 years of age, and 153 patients were ≥ 21 years of age. As such, approximately 10% of the Center's patient population may meet screening criteria for a chronic condition and benefit from an integration of the TRAQ assessment tool to their plan of care. Pediatric gastroenterology is a large subspecialty group within the Center and was chosen for the project due to its size and the possibility of capturing a larger demographic in need of transition services.

Problem Statement

Adolescents and young adults with chronic health conditions do not receive routine HCT readiness assessment as recommended in the national standards for HCT.

Clinical Question

In a multidisciplinary pediatric sub-specialty ambulatory care center, does the implementation of a standardized HCT screening tool (TRAQ) and protocol improve screening rates for adolescents/young adults with chronic gastrointestinal illness and their parents/caregivers?

Aims and Objectives

Studies show CYSHCN are not adequately prepared for HCT (Gray, Holbrook, et al., 2015; Jensen et al., 2017). More specifically, they do not have written transition plans, nor could they recall discussing HCT with their pediatric providers (Gray, Holbrook, et al., 2015; Lotstein et al., 2009). This pilot QI project focused on the HCT process and tool implementation and evaluation for one of the largest pediatric subspecialties (pediatric gastroenterology) with a large population of teenage patients with chronic illness in the Center.

The project aim was to improve standardized, routine HCT readiness screening using the TRAQ and TRAQ-C readiness assessment tool for the pediatric gastroenterology division at the Center by identifying gaps that must be addressed when developing workflow processes, and perhaps, Center exclusive specialty- and/or diagnosis-specific screening recommendations for this large interdisciplinary healthcare system.

More specifically, the objectives of this project were as follows:

- 1) Offer TRAQ and TRAQ-C readiness assessment screening to all patients ≥ 14 years of age and parent/caregiver who presented for chronic disease management related to the subspecialty of pediatric gastroenterology over a 1-month period.
- 2) Compare actual to eligible screening rates.
- 3) Evaluate TRAQ and TRAQ-C readiness responses according to each of the five domains as they related to age and identify common themes.
- 4) Share aggregate screening results and any common themes with the gastroenterology team and practice manager.
- 5) Recommend changes to improve screening compliance.
- 6) Establish a sustainability plan.
- 7) Recommend how HCT screening may be applied more broadly across the Center and/or Center specialties.

Review of the Literature

Though there is an abundance of literature surrounding HCT, there remain gaps in meeting national screening standards. Several state and federal initiatives have been established to improve adolescent health. In Healthy People 2020, the Centers for Disease Control (CDC) included improving the developmental health, general health, safety, and well-being of adolescents and young adults among its goals (Healthy People 2020, 2019). More specifically, one of the goals for this population includes increasing the proportion who receive pediatric to adult HCT planning (Healthy People 2020, 2019).

To assess the current state of HCT screening, a literature search aimed to identify effective screening methods and unveil barriers to screening that influence HCT screening practices in pediatric specialty care centers was conducted. Keywords included *healthcare*

transition, transition to adult care, healthcare transfer, adolescent, ambulatory care, outpatients, outpatient clinic, hospital, chronic condition, chronic disease, chronic illness, TRAQ readiness assessment, quality improvement, assessment, and clinical practice. Using Boolean connectors, the search was performed using PubMed, CINAHL, Medline, Scopus, Joanna Briggs Institute, and Cochrane. Results were restricted to peer-reviewed articles published in English within the last five years (2015-present). This search was followed by a query of grey literature, including professional organization recommendations and clinical guidelines. After eliminating duplicate results, article abstracts were evaluated and/or eliminated based upon relevance to the project. The PRISMA diagram and Table of Evidence can be found in Appendix D and E, respectively.

Inclusion Criteria

Only studies conducted in the United States that discussed the implementation of HCT methods into a busy practice using a QI process in pediatric gastroenterology (or including either pediatric endocrinology or pediatric rheumatology) were included for review. These three pediatric specialties were chosen due to relevance within the project setting.

Exclusion Criteria

Studies conducted outside the United States were deemed less relevant due to prominent health care system and cultural differences. Fundamental variances exist in health care delivery systems across the world compared to the United States. Factors range from health care delivery to insurance directives that influence HCT successes and barriers. In addition, cultural and lifestyle influences similarly affect the acquisition of adolescent autonomy (Newacheck & Kim, 2005; Okumura et al., 2013; Stinson et al., 2014).

Readiness Assessment Implementation Search Results

Of the 40 publications, 16 addressed the clinical question and were critically appraised for evidentiary support. The 16 manuscripts included two systematic reviews with meta-synthesis or -analysis, one narrative review, one organizational position statement with clinical practice guidelines, 11 mixed method original studies, and four QI studies. A small number of studies were added to the review that did not specifically address implementation of a readiness tool because they gleaned valuable perspectives of patients, caregivers, and providers regarding their knowledge of HCT, perception of what is essential in HCT, and actual use in the clinical practice of pediatric gastroenterology. Accordingly, an understanding of these barriers can directly affect the implementation of a readiness tool within clinical practice (Gray, Holbrook et al., 2015). Healthcare transition is a relatively recent construct therefore, few randomized control studies have been performed. One Cochrane Review was appraised. It was not, however, included in this literature review due to the limited scope of pertinent randomized controlled studies and lack of evidence of HCT interventions on successful HCT outcomes in patients (Campbell et al., 2016). Synthesis of the key concepts identified in the literature are presented below.

Updated Clinical Report Guidelines on Healthcare Transition

The original clinical report guidelines on HCT was presented by the AAP, AAFP, ACP, and the Transitions Clinical Report Authoring Group in 2011. Since then, the report was updated and offers several new recommendations based on the most recent literature (White& Cooley, 2018). Along with some revisions of the *Six Core Elements 2.0*, the report also expands the knowledge and complexity of barriers in the implementation process.

This report cites several factors needed to implement and measure a successful HCT process including: (a) key decision makers (stakeholders) from pediatric and adult practices that

include information technology staff, administrators, home care clinicians, and insurers to form a comprehensive team for HCT QI utilizing a plan-do-study-act rapid cycle approach; (b) adult provider education and training of youth with pediatric onset conditions; (c) payment opportunities for HCT; (d) continued funding and research for HCT QI projects; (e) examination of HCT outcomes; and (f) development of pediatric to adult HCT measures for the Child and Adult Core Measure Set and National Quality Forum (White & Cooley, 2018).

Barriers to Readiness Assessment Screening

Provider Knowledge and Practice Alignment

Although, consensus statements regarding HCT within pediatric gastroenterology exist, provider knowledge of such guidelines remains a barrier (Gray & Maddux, 2016). In a non-experimental descriptive study, Gray and Maddux (2016) examined provider knowledge and use of the Core Elements in clinical practice. Of the 141 pediatric gastroenterology providers surveyed, 50% had knowledge of current guidelines and of those, only 14.2% reported having written policies. Additionally, provider approach to HCT differed from current guidelines with merely 0.7% reporting their practice was entirely based on the Core Element structure (Gray & Maddux, 2016). A cross-sectional web-based survey of 175 pediatric gastroenterologists (Bensen et al., 2016) also identified a difference in practice approach and alignment with current guidelines. They revealed less than 25% of providers used any standardized readiness assessment tool in clinical practice. Additionally, providers lacked consensus regarding benchmarks for HCT such as age, life milestones, and self-management skills. As such, clinical practice standards varied, and lacked definable benchmarks to establish structured HCT policies (Bensen et al., 2016).

Other HCT barrier themes based on a systemic review by Gray, Reed-Knight et al. (2018) noted knowledge gaps among providers, poor alignment with clinical guidelines, and lack of consensus among providers regarding “best practices” in HCT as ongoing concerns.

Stakeholder Support

Due to the seminal stage in HCT research, providers have differing opinions regarding clinical recommendations and readiness assessment tools (Gray, Reed-Knight et al., 2018; Nehring et al., 2015). Successful implementation of HCT requires consensus and support from stakeholders, organizational leadership, HCT champions, and provider acceptance in both the pediatric and adult realms (White & Cooley, 2018). The Core Elements serve as guidelines for providers and healthcare systems. However, customization and consensus must be made by the institution, provider, patients, and parent/caregivers. Inclusion of patient and parent/caregiver views proves to be essential in the planning and implementation of HCT processes (Jones et al., 2019). Likewise, administrative support is essential to providers for implementation (Gray & Maddux, 2016). As noted previously, Gray and Maddux (2016) found of 141 pediatric gastroenterologists surveyed across the United States, 25.2% felt there was little or no support for HCT by system administrators. In a separate study, providers report other causes for lack of support for HCT as their own perceptions of time constraints during medical visits, as well as insufficient support staff such as allied health professionals to coordinate care (Gray, Schaefer et al., 2018; Nehring et al., 2015). Many studies thus far have focused largely on the provider perspective. However, Gray, Schaefer, and colleagues (2018) used the TRAQ readiness assessment tool to prioritize and highlight differences in successful HCT transition from provider, parent, and patient perspectives. Significant differences were found between provider and patient perspectives when questioned about issues most important to understand in HCT. An

example of the disparity between patients and providers was elucidated when learning 45% of patients ranked knowledge of health insurance as a top five priority compared 15% of providers (Gray, Schaefer et al., 2018).

Multiple adequate tools assess (Core Element three) transition readiness but they differ in concepts measured, disease specialty, and administration. The TRAQ tool proves ideal as it is standardized, well validated, reliable, non-disease specific, and reimbursable by Medicare (GotTransition 2014-2019; Nehring et al., 2015; Sawicki et al., 2014). In addition to assessment tool consensus among stakeholders, support and interest in the topic of HCT on the part of institutions and providers is vital to implementation and sustainability of the Core Elements in practice (Gray & Maddux, 2016; Jones et al., 2019; Shapiro et al., 2020; White & Cooley, 2018).

The process of HCT requires systems which generally function independently work collaboratively to make system-wide changes in care delivery. For example, Jones et al. (2019) examined seven large health care systems and evaluated the process of HCT improvements over time using the GotTransition Current Assessment of HCT activities. Using a comparative pre- and post-test design, Jones et al. (2019) recruited 55 different types of practice sites including primary, specialty, pediatric, and adult practices to complete a baseline Current Assessment of HCT activities and again at 12-18 months. All sites reported statistically significant improvements in implementing all or some of the Core Elements in HCT. Qualitative analysis was used for feedback from the site and noted, fundamental to implementation was the use of motivated pilot populations to customize and refine transition tools. This theme of champions and leaders for HCT is also shared throughout several QI projects in large healthcare delivery centers such as those within Children's Hospital of Philadelphia and Children's Mercy Hospital of Kansas City (Benson et al., 2018; Gray, Schaefer, 2018; Szalda et al., 2015; Wiemann et al.,

2015). Therefore, provider interest in HCT is a motivating factor for implementation of screening and assessment of readiness to adult care.

Provider Priority of Readiness Assessment

Although providers understand the need for HCT, there is a lack of knowledge regarding valid readiness assessment tools (Shapiro et al., 2020) and no consensus regarding the best clinical practice tool (Nehring et al., 2015). In a recent review of literature of HCT and inflammatory bowel disease, Philpott and Kurkowski (2019) recommended some form of structured readiness assessment tool be used in practice. Additionally, a study of provider perspectives performed by Gray and Maddux (2016) found providers understood the importance of assessment readiness but recognize it is not a priority during visits, especially if the patient's disease state was uncontrolled or unstable. As such, the medical visit focused on specific issues related to disease management leaving little or no time to address readiness assessment tools. Similarly, in a qualitative study of stakeholder interviews regarding barriers to HCT, Gray, Resmini et al. (2015) depicted patient and parent perspectives that transition was important but should only occur when the disease state and life circumstances are stable.

Ease of Integrating Readiness Assessment Tools in Practice

One of the key recommendations for improvements in HCT shared in the 2018 clinical report by White and Cooley is implementation and integration of the Core Elements into EMRs. Readiness assessment tools should be incorporated in EMRs for ease of use, tracking, monitoring of patients identified for HCT (Core Element two), and billing purposes. Integrating a readiness assessment tool in the EMR can be cumbersome for large institutions in part due to the necessary involvement of multiple health system organization standards and various committees that must meet, decide, and approve such changes. A QI study by Wienmann et al. (2015) reported

providers will use an EMR-based transition program if it is user-friendly, manageable, and easily incorporated into the visit. Providers who used the EMR-based program also noted an increase in HCT planning activities including readiness assessment over five Plan, Do, Study, Act (PDSA) cycles (Wiemann et al., 2015) suggesting incorporating valid assessment tools can streamline the HCT process.

Lack of Staffing/Time Constraints

Providers share there is insufficient time during visits to address HCT. In 2016, Gray and Maddux found 71.6% of providers cited lack of time to assess readiness and discuss transition planning within their daily clinic schedule. Furthermore, 73% of providers reported a need for increased staffing while 54.6% requested additional administrative support. While there is consensus among providers that assessing readiness is essential, this study suggests access to appropriately trained staff are required to address skill deficiencies identified by the readiness tool.

Strategies to Improve Readiness Screening

Provider/Patient Time Without Parent/Caregiver

In a descriptive study of barriers to HCT, Gray, Holbrook et al. (2015) report four prominent themes related to barriers. Two of these identify high parental involvement prevents development of self-management skills and provider time alone with adolescents during their medical visit promotes adolescent accountability as it relates to their disease state. Study participants including patients, parents, and providers suggested separation of patients from parents during visits could create independence. Self-management skills are addressed and

assessed in the TRAQ readiness tool and can provide an introduction point for discussion regarding HCT (Gray, Resmini et al., 2015).

Beneficial results of providers spending time alone with their adolescent patients was also observed in a cross-sectional study of patients with eosinophilic esophagitis and their parents (Eluri et al., 2017). The authors found increased provider communication correlated with mastery of readiness to transition (Eluri et al., 2017). Additionally, time alone with providers offered youth and adolescents an opportunity to express concerns in a safe environment while fostering independence and self-management skills (Benson et al., 2018).

Providers have reported difficulty in broaching the topic of HCT in long standing patient relationships. In a QI project, Bond et al. (2019) reported use of a structured readiness tool prompted talking points for providers to initiate discussions about HCT and associated needs.

Time Constraints/Billing Incentives

Issues surrounding the time it takes to provide HCT is a large barrier to implementation. Providers at the Children's Hospital of Philadelphia cite time constraints as the main reason they are unable to follow national guidelines of the Core Elements (Steinway et al., 2017). Such research has prompted HCT leaders to develop incentives for providers who implement a structured readiness tool into clinical practice (White & Cooley, 2018). As a provider incentive, new ICD-10 codes have recently been developed so providers can receive reimbursement from Medicare and private insurance companies to perform screening (White & Cooley, 2018).

Support Staff to Address HCT Planning

Evidence suggests support staff including allied health professionals relieve time constraints for providers during medical visits. Additionally, interventions such as transition clinics, care coordinators, and team approach models have been cited as possible solutions to

promote successful HCT process outcomes (Jensen et al., 2017). A retrospective chart review demonstrated an in-clinic transition coordinator significantly increased transition readiness and self-management skill acquisition and reduced the number of adult patients who remained in pediatric care (Gray, Reed-Knight et al., 2018).

Policy Development to Drive Best Practice

In a systematic review comprised of 57 articles focused on the barriers to HCT across multiple subspecialties, Gray, Reed-Knight et al. (2018) reported essential “best practices” related to HCT and training staff regarding the process of HCT includes provider education to introduce HCT and promote open discussions with patients and parents. Fears and concerns surrounding the topic of HCT exist across pediatric providers, patients, parents, and adult providers and policy planning and development can help alleviate this. In an exploratory study of barriers and recommendations to improve transition, parents appreciated benchmarks for transfer such as age, disease, life stability, and self-mastery skills (Gray, Resmini et al., 2015). The creation of policies with benchmarks shared with patients and their caregivers can alleviate anxiety over the transition process (Nehring et al., 2015).

Disease Stability

Multiple studies have addressed disease acuity in patients as a barrier to HCT (Bensen et al., 2016; Grey, Schaefer et al., 2018; Gray & Maddux, 2016; Gray, Resmini et al., 2015; Jensen et al., 2017; Nehring et al., 2015; Shapiro et al., 2020). Patients, parents, and providers agree a patient’s disease state impacts HCT. Adolescents experience multiple life events during transition to adulthood (White & Cooley, 2018) which creates instability. Patients with chronic disease must adapt to these life event while managing their disease. Several studies conclude that instability of life or disease status could delay HCT planning as this issue is not a priority during

medical visits (Gray & Maddux, 2016; Nehring et al., 2015). As barriers to HCT are unveiled, however, so are the behaviors and concerns of adolescents with chronic illness and their caregivers. Barriers to healthy lifestyles, self-management skills, and psychological concerns can be addressed through the HCT process in an effort to stabilize disease and life states, and in turn, prepare youth for self-management in the adult realm (Gray, Holbrook et al., 2015; Gray, Reed-Knight et al., 2018; Gray, Schaefer et al., 2018).

Theoretical Framework

Model for Improvement

The theoretical framework associated with implementing and evaluating this project was the model for improvement based on the PDSA model (Associates in Process Improvement, 2019) (see Appendix F). The theoretical model for knowledge translation can be adapted for many types of healthcare QI projects and has been the primary model used for implementing initiatives related to HCT in both primary and specialty settings (Gabriel et al., 2017).

Plan-Do-Study-Act

Testing change in the clinical setting is accomplished using the Plan-Do-Study-Act (PDSA) cycle. The planning phase is outlined in detail in the methodology section of this paper. The second phase (Do) entailed implementing the screening tool within a small scale of patients within or part of a larger system. Lessons regarding workflow, provider/patient perceptions, policy guidance (Study) were gleaned and adjusted on a smaller scale before introducing a screening tool to eight other sub-specialties and 25 providers. The study phase incorporated the evaluation of the TRAQ screening tool scores and compared that with assumptions or predictions from the planning stage. Finally, refining the information gleaned from the evaluation provided opportunities to either change workflow of the screening tool, age of implementation, and make

recommendations to develop a formal policy regarding transition (Act). A detailed graphic of the PDSA cycle and implementation of a readiness assessment tool is presented in Appendix F.

Methodology

Project Design

This pilot project applied a non-experimental QI design based on the aims to implement and evaluate workflow and implementation of a readiness assessment tool as part of a structured HCT plan within a large pediatric gastroenterology practice where no formal HCT plan was in place.

Setting

As previously discussed, the project setting was a pediatric ambulatory care center located in central New Jersey that serves over 10,000 patients per year at the main campus location. It houses nine different pediatric specialties with multiple full-time and part-time physicians and nurse practitioners. It is also part of a larger health system that works in conjunction with academic institutions. Therefore, specialty fellows, pediatric residents, medical students, nurse practitioner students, genetic counseling students, and dietitian interns rotate through the Center on a regular basis.

Staffing for this site includes a director of ambulatory care services, practice manager, five on-site scheduling and registration personnel (there is also an off-site contracted scheduling firm), three medical assistants, and one licensed practical nurse. More specifically, the pediatric gastroenterology team consists of five pediatric gastroenterologists, two pediatric nurses, three pediatric dietitians, and one administrative assistant. Although the dietitians are shared among all specialties, much of their time is spent with gastroenterology.

Query of data from the EMR identified approximately 5,800 patients seen by pediatric gastroenterology providers between January 1, 2018 through December 31, 2018. Of the 5,800 patients, 320 were seen during August of 2018 (planned month of project implementation, 2019) and approximately 100 of these fit the eligibility criteria for chronic illness.

Project Population

The project focused specifically on development of a workflow process for implementation of a HCT readiness assessment tool within the pediatric gastroenterology practice. This specialty was selected because of the high volume of patients with chronic disease in need of HCT as compared to the other specialties and lack of a formal HCT readiness tool or process.

Sample Size

It was anticipated the project would yield no more than 50 patient and parent/caregiver dyads to include up to 100 screening tools. This was a QI project and therefore, power analysis was not required.

Recruitment Measures

To obtain eligible patients, the project used convenience sampling over a one-month period as previously discussed. The project summary with directions to patients/providers, recruitment poster, and flyers provided additional information regarding recruitment (see Appendices H, I, J, K).

Inclusion Criteria

Any patient ≥ 14 years of age and their parent/caregiver scheduled for a return patient visit with pediatric gastroenterology at the Center and able to speak, read, and write English, French, or Spanish were included.

Exclusion Criteria

Any patient that presented to the Center for a visit other than pediatric gastroenterology, with a cognitive or learning disability, or had completed the TRAQ and/or TRAQ-C in the preceding 30 days were excluded.

Consent Procedure

Because transition readiness assessment is supported by evidence-based clinical guidelines, part of a national performance measure, included in clinician consensus statements, and considered standard of care, no informed consent was required for this QI project (GotTransition, 2014- 2019; IOM, 2014). Patients and/or parents/caregivers were offered screening but were able to decline.

Risks/Harms

There were no direct risks or harms to patients and/or parents/caregivers who completed the TRAQ/TRAQ-C assessments. The only potential perceived indirect harm that must be noted was, failure to complete screening may delay HCT and as such, may have negative health or health care consequences.

Patient Costs/Compensation

There were no costs to participate in this project. Neither the Center staff, gastroenterology team, patients, nor their parents/caregivers received monetary compensation for their participation.

Interventions

All patients and parents/caregivers who met inclusion criteria were offered screening. The project interventions for this QI project included workflow development and implementation of a standardized readiness assessment to meet the current National Standard of Care for

pediatric to adult HCT. This one-month QI pilot project was carried out in a stepwise manner after institutional, expedited IRB review (see Appendix G for Project Timeline).

Project Preparation

1. The project leader provided a brief in-service for the registration personnel and support staff of the Center about the importance of the TRAQ/TRAQ-C self-assessment questionnaire, project purpose, and workflow screening process.
2. The project leader provided a brief in-service to the gastroenterology team at the Center regarding the project purpose, screening workflow, and importance of the TRAQ/TRAQ-C questionnaire. The workflow process including tool review, billing for service, and how hard copies of the tool were to be handled and scanned into the EMR was provided.
3. The project leader identified two champions to facilitate the project. One led the registration screening process and the other was from the gastroenterology team. This was voluntary.
4. Signs regarding the project purpose and workflow were posted in key areas throughout the Center (e.g., registration area, vital sign stations, and gastroenterology examination rooms). Contact information for the project leader was also provided. Exemplars included in the HCT project were as follows:
 - a. Poster (see Appendix H) was displayed on an easel in the reception area during the project period.
 - b. Flyers (see Appendix I) were displayed at each of the five patient registration kiosks, vital sign stations, and gastroenterology examination rooms.
 - c. Workflow diagrams (see Appendix J) were posted in the registration, vital signs stations, and examination rooms.

- d. Patient/Caregiver instruction sheet (see Appendix K) were attached to a clip board.
5. The project leader alerted all Center staff and gastroenterology team members of the project start in person and via electronic mail.

Screening Workflow

1. The project leader used the EMR to access the patient schedule and identify gastroenterology patients/appointments that met eligibility criteria (return patient visits for patients ≥ 14 years of age). No protected health information was used to complete this screening. The project leader was the only person with access to the patient schedule to identify individuals who met screening criteria. No protected health identifiers were taken or transferred from the EMR.
2. The project leader paperclipped the TRAQ/TRAQ-C questionnaires to the appointment slip for patient visits that met screening requirements.
3. The project leader stocked registration kiosks with extra TRAQ/TRAQ-C screening tools in English, Spanish, and French.
4. During the registration process, the registration personnel identified the patient:
 - a. Had an appointment with a pediatric gastroenterologist,
 - b. Was ≥ 14 years of age,
 - c. Was scheduled for a return patient visit,
 - d. And/or parent/caregiver had not previously completed the tool for a gastroenterology visit,
 - e. And/or parent/caregiver were fluent and able to read English, Spanish, or French, and

- f. And/or parent/caregiver had no gross cognitive disability.
5. Once confirmed, the registration personnel provided the TRAQ/TRAQ-C to the patient/patient-parent/caregiver dyad to complete. Of note, the TRAQ/TRAQ-C are the same tool. The TRAQ was completed by the patient, whereas the TRAQ-C was completed by the parent/caregiver. Each pair of tools (TRAQ/TRAQ-C) were numbered, beginning with 01, 02, 03, etc. in sequential order for comparison.
6. During patient registration and insurance verification, the registration personnel verified patient age, parent/caregiver (if present), and offered TRAQ/TRAQ-C tools to be completed in the reception area.
7. Those agreeing to complete the forms (see below) were provided a clipboard and pen with the following:
 - a. Instructions and contact information for the project leader.
 - b. The numbered forms to be completed.
8. The registration personnel informed the patient and/or parent/caregiver that completion of the forms was voluntary and their decision whether to complete the form would not impact the usual care provided. They also informed the patient and/or parent/caregiver that any questions regarding the tool or answers they provided would be reviewed by the providing gastroenterologist or gastroenterology team member during the scheduled visit.
9. For patients and/or parents/caregivers who did not wish to complete the tool, the registration personnel indicated this on the form (e.g., declined/refused) and placed the blank forms in the locked drop box for tracking purposes.
10. Of note, tools were available in English, Spanish, and French and the appropriate tool was be offered by the registration personnel based on the preferred language of the

patient and/or parent/caregiver. If a tool was replaced based on preferred language, a notation was made by the registration personnel (e.g., provided Spanish tool, provided French tool).

- a. If a patient not previously identified for screening was deemed eligible at the time of patient registration, that individual (staff or gastroenterology team member) offered the tools for completion. The project leader ensured additional screening tools were available at each of the registration kiosks, vital sign areas, and gastroenterology examination rooms.
11. Upon completion, the gastroenterologist and/or gastroenterology team member reviewed and discussed the TRAQ/TRAQ-C with the patient and/or caregiver during the visit.
12. Upon review and discussion of the TRAQ/TRAQ-C assessment tools, the gastroenterology provider billed this service using CPT code 96160 “Health and Behavior Risk Assessment, assessment of transition readiness/self-care skills” (McManus et al., 2016b).
13. The gastroenterology provider tore apart the two copy TRAQ/TRAQ-C forms.
 - a. The original hard copies were labeled with patient name and date of birth and scanned into the EMR.
 - b. The de-identified carbon copy of the tools was placed in one of the two, clearly labeled locked drop-boxes (registration desk and each of the vital sign stations).

The project leader was the only person with the key.

Project Facilitation

1. The project leader collected the contents of each box on a bi-weekly basis and transferred them to a locked file for temporary storage during the project. Once the project was

complete, data was transferred to the office of the Project Investigator and will be stored for five years after project completion.

2. After the first week, the project leader compared the number of patients and parents/caregivers eligible for screening versus those screened. As necessary, the project leader facilitated reminders about the project and, in collaboration with project champions and when necessary, made minor adjustments to workflow to optimize screening within the established protocol (e.g., posted more signs, moved existing signs, reinforced eligibility criteria and instructions for completion with registration personnel).

Project Evaluation

1. After data collection and analysis, the project leader will meet with the director of ambulatory care services, practice manager, gastroenterology team, and other interested parties to discuss the project results. Barriers and successes will be reviewed as it relates to sustainability of this and future projects.

Project Timeline

The overall timeframe from literature review through data analysis was 15 months beginning in January of 2019 and completing in April of 2020 (see Appendix G).

Project Costs

Associated project costs were the sole responsibility of the project leader. Costs included recruitment materials, educational handouts, materials for educational and informative programs, and two locked drop boxes. Costs associated with the dissemination of project findings in terms of professional graphic design for poster presentation were also assumed by the project leader. The anticipated and actual budget is available in Appendix L.

Evaluation

The results of the TRAQ/TRAQ-C readiness assessment tools were analyzed by hand and categorized by age and diagnosis. The number of selected patients were compared to the response rate of the tool. The number of tools reviewed, documented in the EMR, and billed were evaluated. These results were measured by simple means of frequency and reflected by percentages.

Data Maintenance and Security

Completed, numbered, and paired tools were placed in the locked drop box located in two areas of the Center. The TRAQ tools were stored within the project site, in a locked drop box and emptied by the project leader on a bi-weekly basis. No personal health information was entered on the TRAQ/TRAQ-C tools.

Upon project completion, IRB closure, and final writing of the manuscript, all data will be destroyed in accordance with appropriate guidelines. Hard copies of aggregate data were temporarily housed in the office of the project leader and upon completion, moved to the office of the Primary Investigator.

Data Analysis

Quantitative data analysis was performed using Microsoft Excel (version 16.22). Ordinal means of data obtained from Likert-scale survey responses were calculated according to total score and each of the five domains. The patient TRAQ scores were also divided into groups by those patients who came to the visit with a parent and those patients who did not. They were then evaluated for differences using the *t*-test in Microsoft Excel (version 16.22). The TRAQ/TRAQ-C dyads were also evaluated for differences by means of *t*-test correlation.

Results

Implement the TRAQ/TRAQ-C Tool and Compare Screening Rates

A total of 84 TRAQ tool dyads were deemed eligible by the project leader and distributed by registration personnel during the one-month pilot project period. Of the 84 eligible TRAQ tool dyads, 35 TRAQ tools were not completed due to: (a) cancellations or no-show appointments (28), (b) missing TRAQ tools (5), (c) duplicate patient/caregiver dyad (1), and (d) parent refusal (1). At project completion, there were a total of 49 TRAQ and 40 TRAQ-C tools available for analysis. Upon review, seven TRAQ tools were omitted because they were: (a) were outside the age criteria (2), (b) completed by the caregiver due to a cognitive disability of the patient (3), and/or (c) incomplete (2). The remainder of the tools included 42 patients (85.7% return rate) and 33 parent/caregivers (80% return rate). There were 33 TRAQ/TRAQ-C dyads and an additional nine TRAQ tools for patients who attended the appointment without a caregiver/parent. A description of eligibility and implementation of the TRAQ/TRAQ-C tool is shown in Table 4. Of the 42 completed tools, nine (21.4%) were reviewed with the patient and/or caregiver by a gastroenterology team member.

Evaluation of TRAQ/TRAQ-C Results

As previously stated, the TRAQ tool is a 5 point-Likert based scale and, the higher the score the more “ready” a patient is to transition to adult care. There is slight difference among field experts regarding what score defines or determines transition readiness. Wood et al. (2014) established skill mastery for those earning a score of five in all domains whereas Szalda et al. (2015) used a total score of 90 or above to denote skill mastery.

Patient Results (TRAQ)

The age range of TRAQ respondents was 14-25 years, with a mean age of 17 and mode of 16. The age range for those who attended without a parent/caregiver was 17-22 years. Four patient TRAQ tools did not report their age but were included in analysis of overall TRAQ scores. When broken down for age, however, these results were omitted.

With a maximum score of five for each domain, the mean overall score for all domains for patients 18-25 years was 3.95, and for patients ≥ 21 years, it was 4.2. The highest overall mean scores (4.3) were for patients who attended the appointment alone. The sub-category mean scores were as follows: (a) medication management, 3.75, (b) appointment keeping, 3.85, (c) tracking health, 4, (d) talking with providers, 5, and (e) managing activities, 3. Mean scores by question noted patients scored lowest on questions related to financial help (question 12, $M = 2.26$), preparation for medical visit (question 11, $M = 2.69$), and insurance (questions 8 and 9, $M = 2.74$ and $M = 2.86$ respectively). Descriptions of scores can be found in Table 3, Table 5, and Table 8. Comparisons were made regarding patient readiness scores for patients attending the visit with a parent/caregiver versus alone. Patients who attended the appointment without a parent/caregiver ($M = 4.30$, $SD = 0.58$, $n = 9$) scored significantly higher $t(39) = 2.58$, $p = .01$ (1-tail) than those who came with a caregiver ($M = 3.31$, $SD = 1.11$, $n = 33$) (see Table 9 and Figure 2).

Parent/Caregiver Results (TRAQ-C)

The mean overall score of the TRAQ-C tool for parent/caregivers was 4.3. Scores for the five sub-domains were as follows: (a) medication management, 4.0, (b) appointment tracking, 4.0, (c) tracking health, 3.9, (d) talking with provider, 3.6, and (e) managing activities, 4.8.

Comparison of the TRAQ/TRAQ-C Results

The 33 dyads of TRAQ/TRAQ-C scores demonstrated statistically significant differences in mean overall scores using a paired *t*-test. The scores for TRAQ-C ($M = 4.05$, $SD = 0.72$, $n = 33$) versus TRAQ ($M = 3.34$, $SD = 1.12$, $n = 33$) were significantly higher $t(32) = 3.28$, $p < 0.005$ (2-tail) indicating parents/caregivers have a higher perception of their child/adolescent's readiness to transition to adult care than the patient themselves. A description of significant differences between the TRAQ and TRAQ-C scores can be found in Table 7.

Sharing Project Results with Gastroenterology Team.

A formal meeting was proposed with the gastroenterology team and Center administrators and staff to review the data collected and recommendations gleaned from the project. Unfortunately, this meeting has not yet been scheduled secondary to the COVID-19 pandemic.

Discussion and Recommendations

The overall project was a success in terms of screening and workflow, however some protocol elements pertaining to the review and documentation of the TRAQ tool were lacking. Nevertheless, the project provided a vast amount of data to which far reaching implications over several parts of healthcare can be derived.

Implications for Clinical Practice

Stakeholder Buy-In

Essential to project implementation and success was stakeholder buy-in and establishing a systemic approach to the project in conjunction with the Center and more specifically, the gastroenterology team. The team consisted of five physicians, two nurses, three interdisciplinary dietitians, and one administrative assistant. Champions for the project were identified by interest in the topic (Jones et al., 2019). This included one dietitian who manages the tertiary care grant

that supports efforts regarding HCT and one staff member from registration. Critical to the success of the project was the support of the providers, specifically the physicians (Jones et al., 2019). One junior physician supported the project and facilitated meetings between senior members of the team and the project leader.

Despite prior agreement by the gastroenterology team to participate in the project, during the planning stage several providers expressed feelings of hesitancy with the project. Physicians verbalized they feared distribution of the TRAQ/TRAQ-C tools would insight concern among their patients and transfer of care, would imply transfer of care was imminent, and despite the available evidence, an age of 14 was too young for introduction of the tool.

Physicians were unable to agree upon whether or how documentation of the TRAQ/TRAQ-C tools would take place in the EMR and were reluctant to discuss the tool due to time constraints during medical visits. The project leader attempted to mitigate these concerns by discussing them with key providers and reinforcing the benefits of HCT, providing clinical guidelines to each provider, and making available/supplying educational HCT materials to patients and families (see Appendix M).

Despite education and training about HCT, overall, the physicians demonstrated a lack of support for the topic. Of note, no physician reviewed the TRAQ/TRAQ-C tools with the patient and/or parent/caregiver during the pilot period. Several barriers have been cited in the literature to illuminate these findings (Gray, Resmini et al., 2015). HCT is a process that requires careful planning and input from all stakeholders is essential. Administrative support, HCT champions, and gaining a better understanding of barriers noted by key stakeholders may help guide future projects at this site and others regarding HCT.

Provider and Patient/Caregiver Feelings of Loss

Although not elucidated in the project, the provider/patient relationship, especially in CYSHCN, is essential to providing care. As a result, bonds of trust and safety form between the families, patients, and providers over time. Provider feelings of loss exist and cannot be dismissed as an underlying obstacle to HCT (Camfield et al., 2019; Tanner et al., 2017). In a qualitative study of provider perceptions by O'Sullivan and colleagues (2014), providers reported grief and fear of letting go as common themes. Additionally, parents of CYSHCN have reported pediatric specialty care providers and/or children's healthcare institutions are like a "second home" (Gray, Resmini, et al., 2015) and transitioning to adult care provokes worry and anxiety in patients and their caregivers (Maddux et al., 2017). Thus, care needs to be taken to involve providers, patients, and parents/caregivers in the development of HCT processes and policies (White & Cooley, 2018).

Provider Ego

Similar to feelings of loss surrounding HCT on the part of providers, provider ego is a repeatedly identified barrier to HCT. More specifically, the literature supports a general perception by pediatric providers that adult providers would not provide equal or quality care to their patients (Gray, Resmini, et al., 2015; O'Sullivan et al., 2014). During the information session, two gastroenterologists raised questions about the capability of adult physicians to provide care for their older patients. Another study of pediatric endocrinologists found 42% felt adult endocrinologists lacked the knowledge to adequately care for their type-1 diabetes patients (Agarwal et al., 2017). Recommendations to help bridge this barrier include identifying appropriate adult care providers in the planning stage of transition and providing complete and accurate histories through the EMR at the time of transfer (GotTransition, 2014-2019; White & Cooley, 2018).

Recommendations for Clinical Practice

Understanding the barriers as perceived by all stakeholders is essential to building an HCT process at the Center and minimizing those barriers may increase stakeholder support. Therefore, recommendations to integrate a robust system of HCT should include soliciting stakeholder opinions and input regarding appropriate process and workflow changes to facilitate integration. This could be accomplished by systematically surveying all involved parties including patients, parents/caregivers, staff, providers, and administration to identify the five most important issues surrounding HCT. Gray, Reed-Knight et al. (2018) used the TRAQ tool to easily appraise the five most important concepts for patients, parents/caregivers, and providers and identified differences among the groups. Understanding the most important factors as perceived by all stakeholders is essential to implementing new processes.

Policy Implications

Although the workflow and implementation of the HCT tool was a success and the information revealed was interesting, only 12% of patients and 12.5% of the parent/caregiver tools were reviewed by a gastroenterology team member and none were reviewed by a physician provider. As such, the project was unsuccessful in prompting providers to review the available information, begin discussions regarding HCT, and make recommendations accordingly. The overarching purpose of the TRAQ/TRAQ-C tools is to inform providers regarding skill acquisition and deficits and encourage discussions surrounding the transition process with patients and parents/caregivers. Additionally, providers and team members did not document the completion of the TRAQ/TRAQ-C tool in the EMR, and consequently, this effort was not coded or billed.

Reimbursement Issues

Providers and health care systems agree that a significant amount of time is required to adequately address HCT (Bensen et al., 2016; Nehring et al., 2015; Gray et al., 2019). The lack of or perceived lack of time to address HCT readiness was expressed by several senior physicians after the project was underway. One Center performance measure is the number of relative value units (RVUs) used to determine reimbursement dollar amounts for current procedural terminology (CPT) codes (CMS, 2019). In 2019, new CPT codes were introduced to mitigate the extra time needed for successful HCT. These codes, however, pertained to direct contact with a patient or caregiver two days post-hospital discharge and one face-to-face visit within seven to 14 days from inpatient discharge (GotTransition, 2020).

In the ambulatory care setting, HCT planning is not yet reimbursed (McManus et al., 2018). However, reimbursement codes for HCT screening using a validated readiness assessment tool do exist (GotTransition, 2014-2019). There is a CPT code for standardized assessments (96160, Health, and Behavior Risk Assessment) with an RVU of 0.09 (GotTransition, 2020). In comparison, a typical office visit of moderate complexity lasting 25 minutes (CPT code 99214) yields an RVU of 3.06 (GotTransition, 2020). As reported by one senior physician, poor reimbursement with low RVU contributed to the lack of provider support regarding evaluating the tool results and documentation in the EMR.

To address this concern, it may be pragmatic to consider the following approach. If a review of the tool resulted in extended face-to-face visit times with physicians (minimum of 30 minutes), this could be billed using CPT codes 99354-99355 in addition to the E/M codes. Additionally, services provided by allied health staff could use CPT codes 99415-99416 at a marginally lower rate of reimbursement (American Academy of Pediatrics, Division of Healthcare Finance, 2018). Application of these alternative codes may better reflect time

reimbursement for HCT and garner physician support. These and other codes should be discussed with the Center billing service to identify potential codes that may better reimburse for the service provided. A recent roundtable paper examining coding and reimbursement for transition services concluded the top three choices for reimbursement of services include an enhanced fee for service which would include the extra time needed for implementation of transition services, infrastructure incentives, and pay for performance (McManus, White, & Schmidt, 2018).

Recommendations for Policy

The literature indicates the need for a structured process to HCT (White & Cooley, 2018), and consensus among stakeholders regarding key elements in the process are needed before policy implementation. Many studies have identified set benchmarks to alleviate anxiety among stakeholders (Nehring et al., 2015). Therefore, the consensus among stakeholders as to the age of introduction of HCT planning, tracking processes in the EMR, structured transition readiness tool with the frequency of assessments and benchmarks for mastery of readiness, and age range of transfer to adult care are essential to include in policy development (Gray, Resmini et al., 2015). It is anticipated dissemination of this project at the Center will help move a formal process and policy forward.

Healthcare Education Implications

Provider Education

As previously noted, there was a tangible gap in provider knowledge surrounding HCT. Education and training about HCT including the provision of available tools from the GotTransition (2014-2019) clinician toolkit should be structured and include workflow training. This change will provide a better fund of knowledge at baseline (an unrecognized gap by the

project leader before project development) and a more in-depth provider query to better assess hesitancy or resistance. In hindsight, this project may have received better provider support with more robust provider education or in one of the divisions with greater knowledge about and support for HCT and its benefits.

Insurance Education for Patients and Parents/Caregivers

The United States healthcare system has changed since the inception of the Affordable Care Act and despite some improvements, remains fragile (Collins et al., 2019). New laws are surrounding Supplemental Security Income and disability classifications and states can choose continued linkage to health coverage based on these laws. Although new laws expand health insurance coverage to patients until the age of 26, those patients who receive Medicaid or Medicaid HMO must re-apply as an individual at age 19. Analysis of TRAQ/TRAQ-C results from this project are consistent with literature that supports a lack of knowledge regarding health insurance among patients and parents/caregivers (Gray, Holbrook et al., 2018).

Health insurance termination and application processes are cumbersome, lengthy, and require a level of health literacy that may not be present at age 18 (Eluri et al., 2017; Whitfield et al., 2017). Analysis of the TRAQ tool for this project demonstrated low mean scores for items pertaining to insurance presented in Table 8 and Figure 4. The transition and loss of health insurance coverage can be detrimental for CYSHCN, especially those undergoing biologic treatment for inflammatory bowel disease (Philpott & Kurowski, 2019). Healthcare delivery systems are culpable as support systems and education surrounding the complexities of health insurance can enhance transition readiness and minimize risk for care and insurance gaps.

Patient Self-Management Skills

There were significant differences in the readiness scores between patients who came to the Center without a caregiver and those who did not. Gray, Holbrook, et al. (2015) found of 195 patients with IBD ages 16-25 years, only 5.6% demonstrated mastery of the TRAQ assessment (defined by scoring a five on at least 18 of the 20 questions). In this project, only two of the nine patients who came without a caregiver ages 17-22 would be considered at the mastery level for readiness to transition as defined by Gray, Holdbrook et al., 2015. Thus, this project reinforces patients who meet the age criteria for transfer to adult care are still not prepared to transfer as measured by the TRAQ tool. This project identifies patients who meet the age criteria for transfer but lack the self-management skills necessary for transfer supporting the current literature that patients are not prepared for HCT (Bensen et al., 2016; Gray, Holbrook, et al. 2015; Gray, Schaefer, et al., 2018; Jones et al., 2019; White et al., 2018).

Recommendations for Healthcare Education

This project elucidates the need for provider education in addition to continued health and healthcare education for older adolescent and young adult patients regarding HCT. In a study using the TRAQ tool, Gray, Holbrook et al. (2015) noted only 5.6% of patients reached the benchmark for mastery of skills. In this study assumptions were made that skills not mastered are being performed by the parent/caregiver. Educational implications for the provider include involving the family in the transition process and offering guidance to parents regarding how to assign and relinquish tasks to the patient (Gray, Holbrook et al., 2015). Additionally, implementing a formal mechanism to provide written, audio, and/or video education surrounding HCT, insurance, and health care provider resources available at the state and/or local level would help close this gap. Targeted education surrounding disease management could also enhance HCT readiness.

Healthcare Quality Implications***Lack of Adult Care Providers***

Lack of identifiable adult care providers was a common theme during informal discussions with the gastroenterologists before project implementation. Three of the five physicians agreed they were not comfortable referring their patients to providers listed in transition apps such as “Doc4me” created for patients on the cusp of transitioning by professional organizations like the North American Society of Gastroenterology, Hepatology, and Nutrition (NASPGHAN, 2019). Barriers to identifiable providers include participation with insurance and adult provider lack of adequate medical knowledge of patients requiring complex care (Tuchman et al., 2008; Wright et al., 2018). The literature supports several interventions listed below to mitigate this barrier.

Allied Health Support

Currently, the Center does not have a designated person to address HCT and multiple studies cite the need for allied health to address HCT and implementation. Some studies report transition coordinators as a solution to this concern (Annunziato et al., 2013; Davis et al., 2014). This project highlights provider time and reimbursement constraints and need for support services to assume some of the work required to successfully transition patients promptly.

Integration Within the Electronic Medical Record

There is no formal standardized readiness assessment tool integrated into the EMR at the Center. Essential for consistency, tracking, planning, and transfer, implementation of the TRAQ or a similar tool is recommended (GotTransition, 2014-2019). The promoting interoperability programs funded by CMS provide incentive payments to practices adopting the use of certified EMR technology which has transition services listed as meaningful use (CMS & HHS, 2019).

Integrating a readiness assessment tool in the EMR could incorporate additional measures for meaningful use with prompts and “quick text” to ease documentation burdens and integration of HCT educational materials based on age could reduce some of the burden from providers.

Including the tool into EMR has the potential to ease clinic workflow, address time management concerns, and provide essential documentation needed to code and bill the service (Gray, Resmini et al., 2015). The creation of streamlined planning systems within the EMR focused on transitioning adolescents to adult healthcare could facilitate improved compliance with CMS guidelines pertaining to health information technology (GotTransition, 2014-2019).

Recommendations for Healthcare Quality Improvement

Recommendations for healthcare planning must include the introduction of a readiness tool into an EMR for ease of use. Similar to the TRAQ, Wiemann et al. (2015) introduced a transition planning tool for readiness assessment to a healthcare delivery system over five PDSA cycles. The goal of increasing HCT planning among patients aged 16-25 with the introduction of the tool increased to 80% with the use of providers reporting they used the tool to engage their patients in transition planning (Wiemann et al., 2015). Weissberg-Benchell and Shapiro (2017) report transition coordinators and transition clinics are useful for HCT planning and process structure. Gray, Holbrook, et al. (2019) also report significant changes in acquisition of patient readiness skills after implementation of a medical social worker as a HCT coordinator in a large irritable bowel disease clinic. Healthcare transition coordinators can assess readiness skills, develop interventions in knowledge deficits, and promote and facilitate communication between adult and pediatric services. Additionally, the use of an allied health provider as a transition coordinator for the Center could increase adult provider availability by mitigating the barriers

using strategies such as list serve, professional organizations, and disseminating HCT knowledge and training programs to adult provider partners.

Plan for Sustainability

Recommendations for sustainability within the gastroenterology specialty can guide workflow, implementation, and policy development not only for this division but across all Center sub-specialties. Several PDSA cycles should be analyzed to establish consensus among stakeholders and further assess workflow and best practices surrounding the review process (including education and referral processes), documentation, and coding for the gastroenterology specialty (Jones et al., 2019). With minor revisions, the project workflow could be expanded to other specialties within the Center. These are small efforts that may aid in promoting the continued use of a readiness assessment as a best practice in HCT. However, for robust practice change, an interdisciplinary HCT Task Force should be created to develop recommendations regarding process and policy, determine the validated HCT tool(s) to be used, implement and evaluate PDSA cycles, and facilitate the integration of the tool, available resources, and HCT documentation (including trend capability) into the EMR (Gray, Remini et al., 2018; Steinway et al., 2017). In the absence of this, the most feasible recommendations for sustainability include continued use of the TRAQ/TRAQ-C tools distributed to all patients ≥ 14 years of age scheduled for a return patient visit regardless of diagnosis (without pre-screening for chronic disease).

Limitations

There were several limitations to this project. Upon review of the TRAQ/TRAQ-C results, the weight of the statistical difference between scores may be flawed and consideration should be taken when interpreting these findings. As noted, the TRAQ-C tool instructions may have been misunderstood by the parent/caregivers to reflect their ability instead of the parent's

perception of their child's ability. Additionally, this project included a small sample size from only one pediatric specialty within a large pediatric subspecialty center and the project was only one month in duration. Although the project provides insight regarding the infrastructure needed to guide workflow, provider, and patient knowledge gaps and solidifies the need for formal policy moving forward for this specialty within this Center, the needs of providers, ancillary personnel, and patients and their parents/caregivers cannot be generalized.

Lessons Learned

Project Preparation

The project leader underestimated the baseline knowledge of providers with respect to HCT. More formal education should have been provided for the gastroenterology team as well as the practice manager and registration supervisor. The necessity for HCT champions and administrative support is essential for proper implementation and sustainability in any QI project and especially, one involving HCT (Gray, Reed-Knight et al., 2018; Gray et al., 2019; Gray & Maddux, 2016; Jones et al., 2019; Shapiro et al., 2020; White & Cooley, 2018). Although HCT champions were identified and facilitated project success, registration personnel did not always follow the workflow process and physician provider engagement and participation buy-in fell short to include lack of TRAQ/TRAQ-C review with the patient and/or parent/caregiver and EMR documentation and billing. More in-depth education for the registration staff and gastroenterology team as it pertains to HCT, the project, eligibility criteria, and workflow would have been beneficial.

Provider Reluctance to HCT

In addition to provider knowledge, the project leader miscalculated physician fear regarding the transition process. Several factors that contributed to project resistance shared by

providers during the project included: (a) fear regarding the negative financial impact of losing patient volume with successful HCT, (b) concern the tool would incite fear in the patient and/or parent/caregiver they were imminently being discharged from the clinic, and (c) inexperience/discomfort in discussing, answering questions, and knowing the available resources for patients and parents/caregivers to guide HCT. A stronger foundation in HCT education should have been provided and the project leader should have better articulated the plan and anticipated provider concerns before the project start.

Several recommendations for improvement are as follows. Education and training about HCT including provision of available tools from the GotTransition (2014-2019) clinician toolkit should be structured and include workflow training. This will not only provide a better fund of knowledge at baseline (an unrecognized gap by the project leader prior to project development) and more in-depth provider query to better assess hesitancy or resistance. In hindsight, this project may have received better provider support in one of the other eight subspecialties, a division with greater knowledge about, and support, for HCT and its benefits.

Another consideration includes changing the language used on recruitment posters and flyers. The word choice of “Move on Up” may have incited concern surrounding transfer among patients, parents/caregivers, and providers and as such, an alternative phrase should be considered. Such phrasing could include “Help Us Help YOU” or “The More You Know” a current and frequently used public service announcement may be received more positively by patients, parents/caregivers, and providers.

Patient and Parent/Caregiver Demographics

To minimize confusion when completing the demographic portion of TRAQ/TRAQ-C forms, presenting the information with more clarity is important. More specific information

regarding underlying diagnosis, number of years coming to the Center for treatment, gender, and grade level may be beneficial in elucidating additional information that may include opportunities to establish peer support/support groups and educational activities surrounding HCT across disciplines.

Improved Instruction for TRAQ/TRAQ-C Completion

The project noted a potential for misunderstanding TRAQ/TRAQ-C completion instructions during the first week of the project when several TRAQ-C forms revealed 14-year-old children scored at the highest level (5, *I do this all of the time*). Confirmation of this finding was noted when a member of the gastroenterology team reviewed the TRAQ/TRAQ-C with one family. Future projects must include more clear instruction or perhaps, recommending this clarifying change to the TRAQ tool authors.

Eligibility of Cognitively Impaired Adolescents

The project excluded cognitively delayed or impaired patients but moving forward, TRAQ tools should be offered to the parent/caregivers of these individuals and used to assess the ability and readiness potential of the parent/caregiver. In these circumstances, understanding the parent's skill level is essential in assessing readiness for HCT (Gray, Resmini et al., 2015). More careful time in addressing these issues before the start of the project may have gleaned better insight regarding patient and provider readiness to transition by the gastroenterology team and provide more detailed guidance surrounding policy rather than process/workflow development.

Dissemination and Professional Reporting

Project dissemination will take place across several venues. The final project report will be submitted to the investigational site (providers, staff, administrators) for their review.

Presentation of findings will take place for providers involved in the project at the project site

and/or to specialty and primary care providers during Pediatric Grand Rounds. Upon revision, the project manuscript will be submitted for publication in a peer-reviewed journal such as *Transitioning of Adolescent Medicine*, *The Journal of Pediatric Healthcare*, *The Journal of Pediatric Nursing*, or *Pediatric Nursing*. Podium and poster presentation abstracts will be submitted for presentation at annual conferences of the National Association of Pediatric Nurse Practitioners, The Society of Pediatric Nursing, and/or the American Academy of Nurse Practitioners. Lastly, the project will be presented at the School of Nursing, Doctor of Nursing Practice Poster Day on April 20, 2020 and made available at the Center.

Conclusions

Congruent with the literature, this pilot QI project illuminated barriers to HCT including knowledge deficits, lack of consensus among guidelines and benchmarks for HCT, and provider resistance to HCT. With gained knowledge from this project, it is clear the Center needs more provider-focused education regarding The Six Core Elements of Transition. More formal education in terms of experts in the field presenting at Pediatric Grand rounds could also be helpful in moving this forward across all Center specialties. In terms of implementation and sustainability of a readiness assessment tool across divisions, deeper discussions with providers and ancillary personnel are recommended to identify real and perceived barriers for providers and specialties. Recuperation of time spent on readiness transition could be explored if providers or allied health professionals review the tool with their patients and families. Providers and health systems that bill and code for the tool/tool completion regularly may better inform Medicare that HCT is important to the health and well-being of these soon to be adults and elevate reimbursement. For sustainability, this QI project will need to be followed by comprehensive education, assessment, reeducation, and reassessment to ensure policy and

process are established that address these barriers and garner support and consensus among all stakeholders. Once this has been established, another pilot should be conducted to determine if the process works within this complex system and if so, a formal HCT policy could be created and formalized.

This project also demonstrated several positive factors as it pertains to HCT. The project implementation of screening patients for transition readiness was successful as the target number of patients set was obtained. If the assessment tool could be sustained, the Center would be one step closer to meeting the national performance measure standard that all adolescents receive some HCT planning as part of their health and well-being (National Survey of Children with Special Child Health Care Needs, 2017-2018). Dissemination of the results of this pilot project at the Center will serve as the stimulus for discussion, innovation, and implementation of additional and more complex HCT projects in the future.

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[TRAQ English, TRAQ French, TRAQ, Spanish]

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Table 1*Six Core Elements of Healthcare Transition 2.0*

Core Element	Age	Description of Element
Transition policy	12	Develop, educate, disseminate a transition policy beginning at age 12-14.
Tracking and monitoring	14	Establish criteria and process for identifying youth reading for transition. Enter data in a registry in EMR for tracking process of 6 core elements.
Transition readiness	16	Conduct readiness assessment regularly, identify needs, and reassess patients.
Transition planning	18	Develop and update an individualized plan of care, prioritizing findings, goals, and actions.
Transfer of care	18-22	Prepare a package of care, date of transfer, emergency plan, a medical summary, and legal documents.
Transfer completion	23-26	Contact patient 3-6 months after the transfer of care to confirm transfer, collaborate with adult provider to establish communication.

Note. This table represents a summary of the Six Core Elements of Health Care Transition 2.0 Adapted from GotTransition/Center for Healthcare Transition Improvement (2014-2019).

Table 2*Current Validated Transition Readiness Assessment Tools*

Name of Readiness Assessment Tool	Self-administration	Parental Component	Description	Validity and Reliability	Custom	Language(s)
TRAQ 5.0	yes	not validated	20 questions 5-point Likert	0.93 reliability	no	English Spanish French
GotTransition	yes	no	23 questions 3-point Likert		yes	English Spanish
TRxANSITION	no	no	32 questions 3-point Likert	0.71 reliability	no	English
STARx	yes	yes	18 questions Self-report 5-point Likert	0.80 reliability	no	English Spanish
AM I ON TRAC? British Columbia	yes	no	14 questions Likert Scale Age 12-19	0.84 reliability	no	English
Boston Children's ADAPT	yes	no	26 questions Age 16-17 Self-report	0.74 alpha coefficient	no	English Spanish

Note. This table represents the current readiness assessment tools recommended in the clinical guidelines for healthcare transition readiness assessment. Adapted from “Validated Transition Tools” by GotTransition/Center for Healthcare Transition Improvement (2014-2019).

Table 3*Means and Standard Deviations of TRAQ and TRAQ-C Scores with Subdomains*

TRAQ Components	TRAQ Patients n = 33		TRAQ-C Parents/Caregivers n = 33	
	M	SD	M	SD
Medication management	3.35	1.29	4.0	1.05
Appointment keeping	2.94	1.40	4.0	1.14
Tracking health issues	2.83	1.26	3.9	1.39
Talking with providers	4.44	1.14	3.6	1.42
Managing daily activities	4.0	1.07	4.8	0.37
Overall Score	3.31	1.11	4.3	0.87

Note. This table demonstrates the means (M) and standard deviations (SD) of the TRAQ/TRAQ-C dyad scores (n = 33) based on each subdomain.

Table 4*Characteristics of TRAQ Tool Implementation*

TRAQ Tool Eligibility	TRAQ Tools			
	Patient		Parent/Caregiver	
	n	%	n	%
Pre-Selected by PL	84	-	84	-
Appointments cancelled	28	33	28	33
Missing	5	5	5	5
Refused	1	1	1	1
Duplicate	1	1	1	1
Returned	49	58	40	47
Total eliminated	7	14	7	17
Outside age criteria	2	4	2	.05
Cognitive delay	3	6	3	.07
Incomplete data	2	4	2	.05
Total TRAQ tools included	42		33	

Note. Four patient tools did not report age. Nine patients came without a parent. There were a total of 33 patient and parent/caregiver dyads tools for review and comparison.

Table 5*Demographic Characteristics of Patients*

Patient Age in Years	Number of Patients	Percent of Total Patients
14	2	4.7
15	7	16.6
16	7	16.6
17	6	14.2
18	6	14.2
19	3	7.0
20	1	2.0
21	3	7.0
22	2	4.7
25	1	2.0
No age reported	4	9.5

Note: There were a total of 42 patients (n = 42).

Table 6*Characteristics of Patients Without a Parent/Caregiver*

Patient Age in Years	Number of Patients	Percent of Total Patients
17	2	4.7
18	2	4.7
19	0	0
20	1	2.3
21	2	4.7
22	2	4.7

Note: Nine patients attended the visit without a parent/caregiver ($n = 9$). This represents 21.4% of the total sample size ($n = 42$).

Table 7*Comparison Between TRAQ and TRAQ-C Results*

	TRAQ	TRAQ-C	Mean Difference (SD)	95% CI of the difference	p value
n = 33 dyads	3.34 (1.11)	4.05 (1.05)	0.74 (0.06)	0.28 (1.19)	p < 0.005

Note. Using a paired t-test, there were significant differences between overall patient and parent/caregiver means. The above findings suggest parent/caregivers overestimate their child's readiness to transition to adult care.

Table 8*Mean TRAQ and TRAQ-C Scores Based on Question*

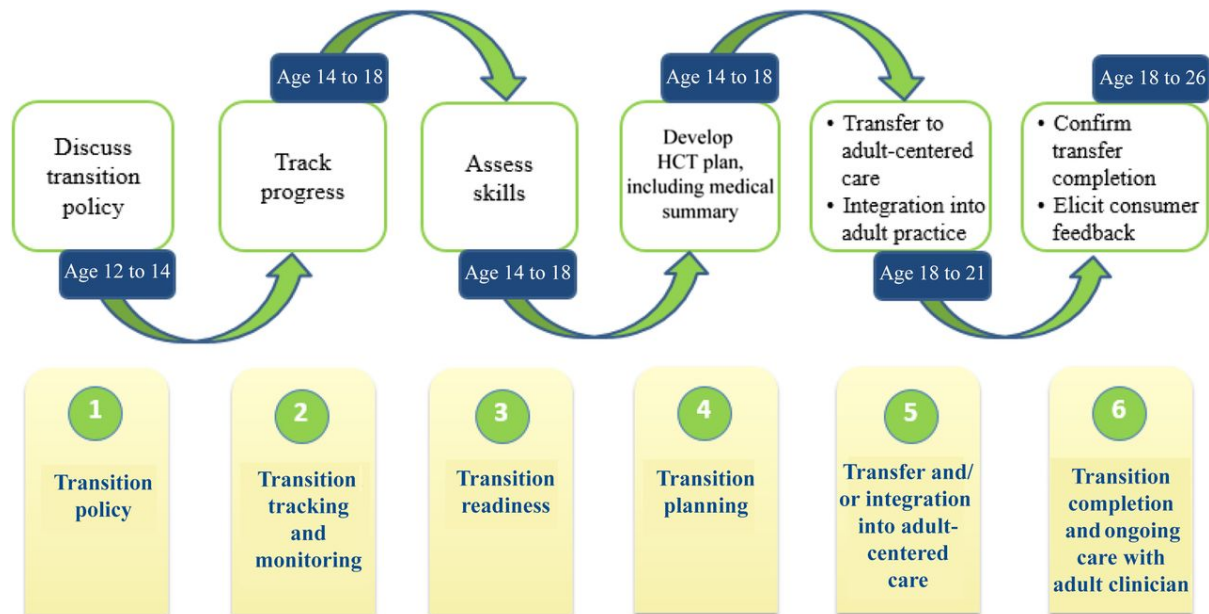
TRAQ Questions		Patient	Caregiver/Parent
1	Do you fill a prescription if you need to?	3.19	3.58
2	Do you know what to do if you are having a bad reaction to your medications?	3.43	3.58
3	Do you take medications correctly and on your own?	4.36	4.64
4	Do you reorder medications before they run out?	3.5	4.12
5	Do you call the doctor's office to make an appointment?	3.45	3.94
6	Do you follow-up on any referral for tests or check-ups or labs?	3.43	3.97
7	Do you arrange for your ride to medical appointments?	3.74	4.21
8	Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?	3.4	3.94
9	Do you apply for health insurance if you lose your current coverage?	2.74	3.79
10	Do you know what your health insurance covers?	2.86	3.7
11	Do you manage your money & budget household expenses (For example: use checking/debit card)?	2.9	3.85
12	Do you fill out the medical history form, including a list of your allergies?	3.6	4.3
13	Do you keep a calendar or list of medical and other appointments?	3.52	3.79
14	Do you make a list of questions before the doctor's visit?	2.69	3.48
15	Do you get financial help with school or work?	2.26	2.85
16	Do you tell the doctor or nurse what you are feeling?	4.48	4.79
17	Do you answer questions that are asked by the doctor, nurse or clinic staff?	4.55	4.88
18	Do you help plan or prepare meals/food?	3.64	4.24
19	Do you keep home/room clean or clean-up after meals?	4.4	4.6
20	Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)	4.26	4.2

Note. Options for scoring: 1= No, I do not know how; 2= No, but I want to learn; 3= No, but I am learning to do this; 4= Yes, I started doing this; 5= Yes, I always do this.

Table 9*Mean TRAQ Scores of Patients With and Without a Parent/Caregiver*

TRAQ Domain	Patients Without Caregiver n = 9		Patients With Caregiver n = 33	
	M	SD	M	SD
Overall score	4.3	0.58	3.21	1.05
Managing medications	4.47	0.55	3.32	1.14
Appointment keeping	4.25	0.77	2.88	1.39
Tracking health	3.83	0.90	2.77	1.42
Talking with providers	4.78	0.50	4.30	0.31
Managing activities	4.48	0.93	3.74	0.87

Note. This table demonstrates the means (M) and standard deviations (SD) of the TRAQ scores of patients who came to the visit with a caregiver (n = 33) and of patients who came to the visit without a caregiver (n=9) based on each subdomain

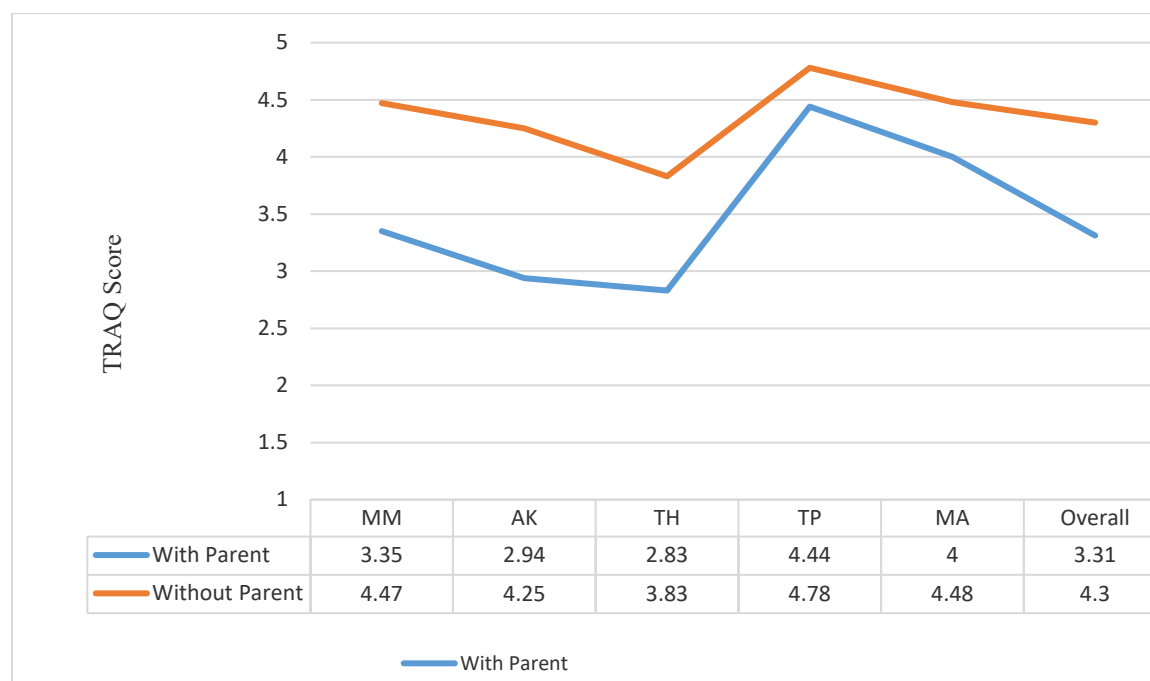
Figure**1***Six Core Elements of Healthcare Transition Aligned with Age*

Note: Adapted from “Timeline for Introducing the Six Core Elements into Pediatric Practice” (White & Cooley, 2018).

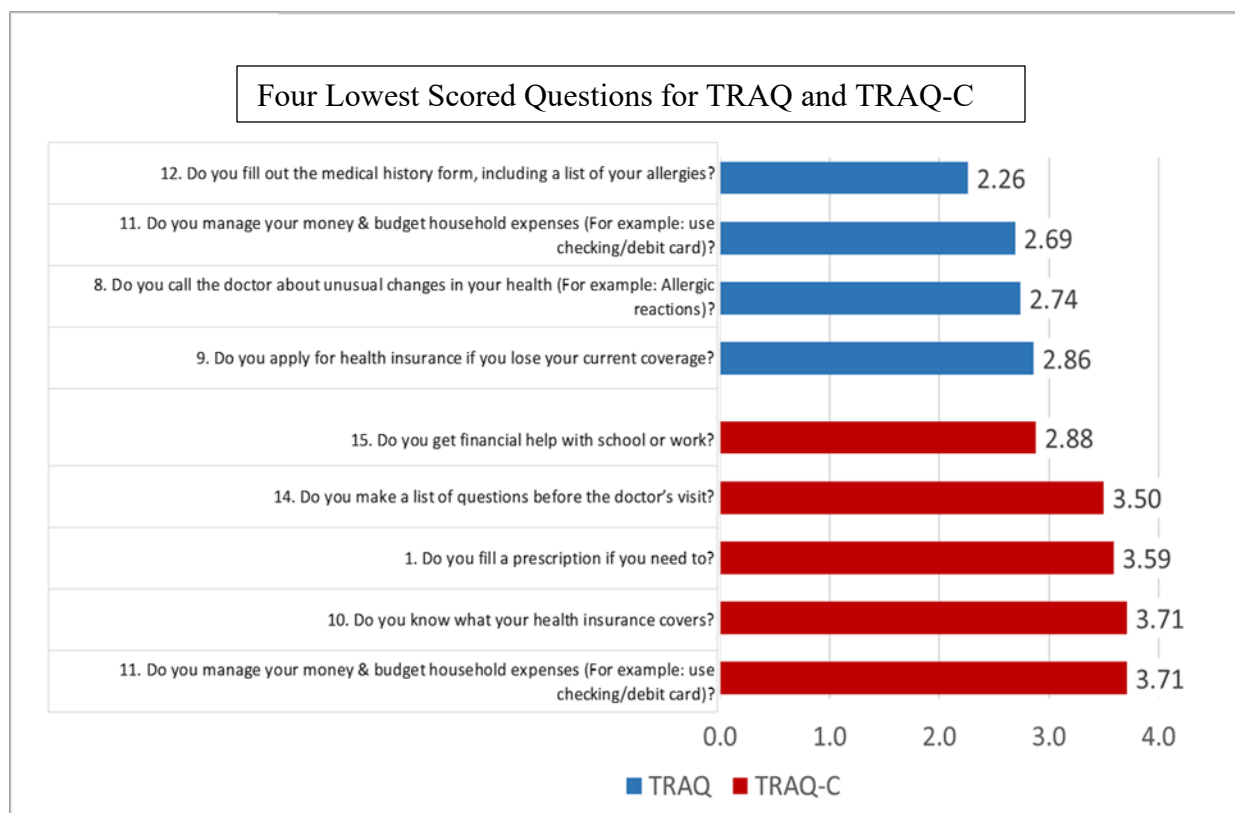
Figure 2*TRAQ Mean Scores Based on Age in Years*

Figure 3

TRAQ Mean Scores of Patients With and Without a Parent/Caregiver Present



Note. MM = medication management; AK = appointment keeping; TH = tracking health; TP = talking with providers; MA = managing activities; Overall = the mean of all five categories.

Figure 4*Lowest Scores for TRAQ and TRAQ-C*

Note: This table represents the four questions that scored the lowest on TRAQ and TRAQ-C assessments.

Appendix A

TRAQ Readiness Assessment Questionnaire 5.0 English

Patient Name: _____ Date of Birth: ____/____/____ Today's Date ____/____/____ (MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level. Check here if you are a parent/caregiver completing this form. ☐

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Appendix B

TRAQ Readiness Assessment Questionnaire 5.0 Spanish

Patient Name: _____ Date of Birth: ____/____/____ Today's Date ____/____/____ (MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level. Check here if you are a parent/caregiver completing this form. ☐

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Appendix C

TRAQ Readiness Assessment Questionnaire 5.0 French

Patient Name: _____ Date of Birth: ____/____/____ Today's Date ____/____/____ (MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

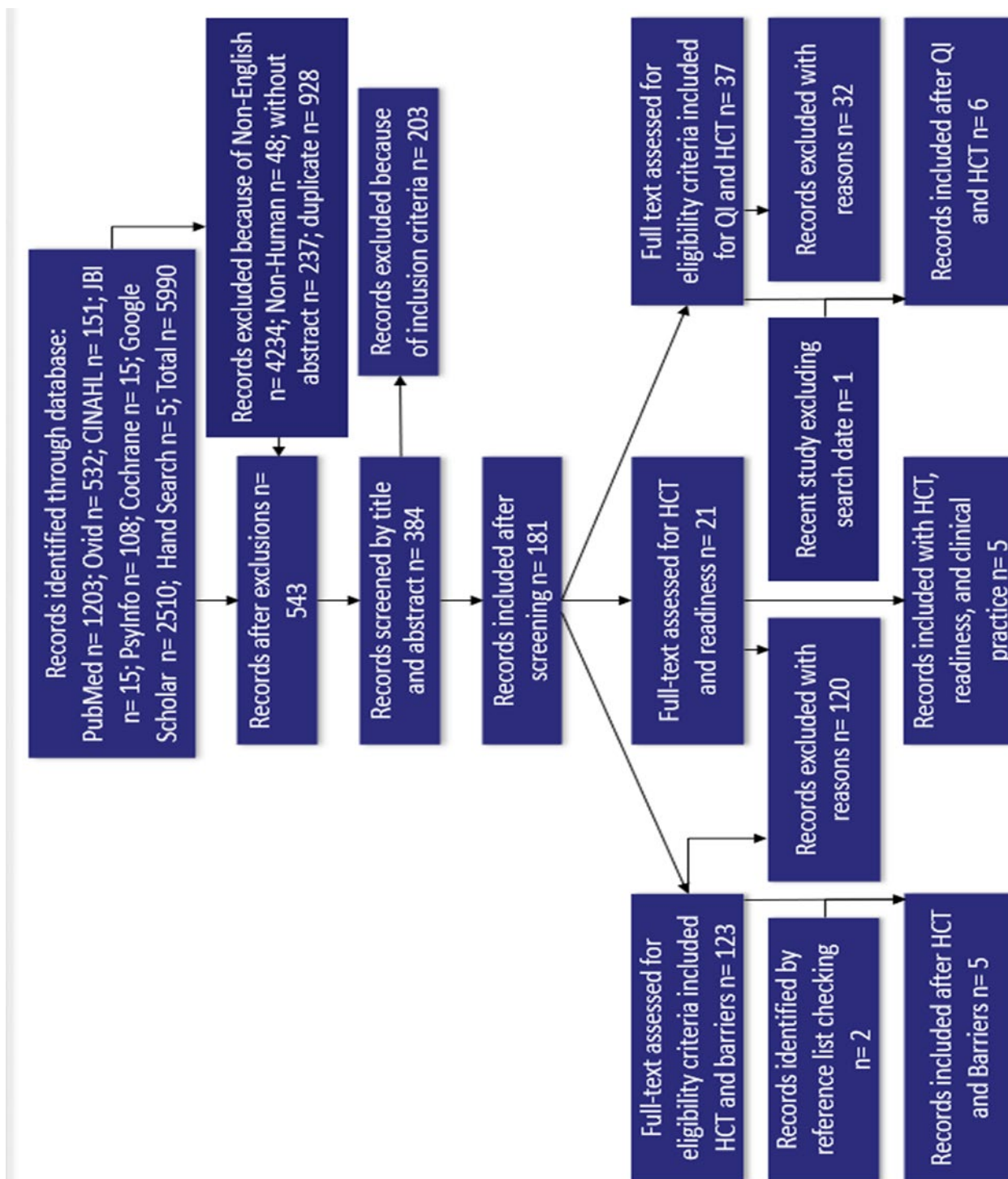
Directions to Youth and Young Adults: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level. **Check here** if you are a parent/caregiver completing this form. ☐

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Appendix D

PRISMA Diagram



Appendix E

Table of Evidence

Article #	Author Date	Evidence Study Type	Sample, Size and Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
1	Gray & Maddux (2016)	Non-experimental, descriptive study	<p>n=141 pediatric gastroenterology providers across the US. Physicians: 82.3% Nurse Practitioners: 6.4% Physician Assistants: 0.7% Nurses: 2.8% Social Workers: 2.8% Psychologists: 0.7% Dieticians: 0.7% Medical Assistants: 0.7% Fellows others 2.8%</p> <p>Practice setting: Children's Hospital (free standing): 47.5% Children's Hospital (part of the larger hospital): 41.8% Private Practice: 8.5% Other: 2.1%</p> <p>1656 individuals emailed with 166 responses and 25 incomplete surveys. 47 item online survey designed to examine transition practices of providers, and their opinions of institutional policies, specific strategies for preparation, barriers to care, and resources needed.</p> <p>The extent to which practices adhere to transition guidelines were also evaluated.</p>	<p>50% of respondents were not familiar with the AAP guidelines.</p> <p>Of the 50% that were familiar with the guidelines, 28.4% used some of the elements in practice.</p> <p>14.2% of respondents reported having written guidelines in their practice or institution.</p> <p>45.4% of sample introduced transition at 15-17; 3 years later than recommended in the clinical guidelines</p> <p>25% of the sample introduced transition between the ages of 12-14y.</p> <p>25.2% of providers perceived having "no" or "low" support from institutions/administrative support.</p> <p>71.6% of respondents endorsed more time in clinic to focus on transition with patients.</p> <p>53.9% of respondents endorsed reimbursement for transition-related services.</p>	<p>Low response rate of 8.5%.</p> <p>24.5 % of practices institutions are representative of those contacted.</p>	III High

Article #	Author Date	Evidence Study Type	Sample, Size and Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
2	Gray, Schaefer, et al., (2018)	Systematic review using the Socioecological Model of AYA Readiness for Transition (SMART) to summarize the literature on barriers to transition.	<p>n = 57 Quantitative = 24 Qualitative = 25 Mixed-Method = 8 PRISMA</p> <p>Inclusion Criteria English speaking Focused on transition from pediatric to adult health care Focused on AYAs (< 25) Included a chronic illness group Presented original data on barriers to transition US</p> <p>13 different chronic illnesses represented Out of the 57 studies, diagnoses included the following: Asthma Cancer Chronic kidney disease Congenital heart disease Cystic fibrosis Diabetes Epilepsy HIV HCL Irritable bowel disease Sickle cell disease Transplant Systemic lupus</p>	<p>Identified system-level barriers to transition readiness vs. individual barriers.</p> <p>11 different barriers identified: Demographic/Culture Access/Insurance Health Status/Risk Neurocognition Development Knowledge Skills/Efficacy Belief/Expectations Goals Relationships Psychosocial Functioning</p> <p>4 common barriers exist among the chronic illnesses: Relationships Belief/Expectations Skills/Efficacy Access/Insurance</p> <p>Readiness for transition should be regularly assessed and in early adolescence so that there is time to address barriers.</p> <p>Healthcare training in transition practices to include for providers how to have candid discussions of transition with their patients.</p>	<p>Researcher bias.</p> <p>Quantitative studies were descriptive surveys and largely were not hypothesis driven.</p> <p>No leading theoretic framework is guiding research.</p> <p>No way of quantifying articles of varying methods and all articles were weighed equally.</p>	III High

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
3	White & Cooley (2018)	Clinical Report	Not applicable	<p>Cites the updated Six Core Elements of HCT 2.0; specifically gives recommendations towards the integration of these elements into specialty practices and other healthcare delivery systems.</p> <p>Supports the development of quality improvement projects to implement the 6 Core Elements into practice by working directly with patients, parents, and healthcare system information technology departments to incorporate the elements to the electronic medical record to improve workflow.</p> <p>Supports the need for further initiatives and innovative practices to investigate successful HCT outcome measures.</p> <p>Gives specific recommendations towards reimbursement and coding for implementation of a validated Readiness Assessment Tool</p> <p>Supports enhanced training of providers and patients about HCT practices through continuing medical education credits, integration into residency programs.</p>		IV High

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
4	Jones et al. (2019)	Non-experimental, pre/post-test quality improvement mixed methods design	<p>National HCT learning network shared strategies to improved HCT using the Six Core Elements. Leaders of seven health care delivery systems in the network recruited 55 practice sites, 12 primary care, 43 specialty care, 47 pediatric care, and 8 adult care.</p> <p>A quantitative Current Assessment (CA) tool measured activities related to the implementation of any one of the 6 core elements into clinical practice. One was completed at baseline and one was completed 12-18 months later.</p> <p>Pre and post-test were conducted overall, and health leaders of all 7 health systems described qualitatively factors impacting HCT implementation processes.</p>	<p>Quantitative results noted significant improvement ($p < 0.05$) in HCT activities as measured by the Current Assessment tool—lack of time to incorporate HCT tools easily and quickly into the EMR.</p> <p>Scores increased from a baseline average of 10.9 to 17.9 after 12-18 months.</p> <p>Qualitative findings regarding initiating motivation to invest in HCT QI: Stakeholders concern of HCT process, young adults lost to follow up, and timely access to specialty pediatric care needed to be improved.</p> <p>Learning network members cited importance of stakeholder buy-in and identifiable champions for HCT. Using small pilot populations to begin the process.</p> <p>Lack of time to incorporate HCT tools easily and quickly into the EMR.</p> <p>Support staff was needed to implement HCT process.</p> <p>Element #3 Transition readiness implementation were 1) deciding on how and when the assessment would be given, 2) creating written resources and scripted anticipatory guidance for addressing self-care skill needs, and 3) incorporating the result of the assessment into the EMR.</p> <p>Increase administrative support increase time to implement HCT; local QI teams are essential planning in clinics.</p> <p>Knowledge of QI methods were helpful prior to beginning and QI transition process.</p> <p>Variability of strategies to disseminate the readiness assessment. Some through the patient portal and web-based design.</p> <p>Motivated pilot population to refine and customize transition tools.</p>	<p>Study examined process measures, not outcome measures.</p> <p>Unable to generalize results to systems where clinical champions and senior leadership are not motivated.</p>	III Good

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
5	Bensen, et al., (2016)	Non-experimental cross-sectional web-based survey	<p>Online survey was distributed by email to the North American Society of Pediatric Gastroenterology, Hepatology, and Nutrition.</p> <p>Quantitative and qualitative analysis was performed.</p> <p>1423 surveys were distributed with 175 respondents.</p> <p>N = 175 Pediatric gastroenterology providers in academic institutions across North America.</p>	<p>Addressed the barriers associated with an effective transition and transfer process as perceived by pediatric gastroenterology providers across the US.</p> <p>81% cited parent/patient attachment to providers.</p> <p>74% Patient attachment to pediatric providers.</p> <p>64% Patients emotional or cognitive delay.</p> <p>56% Providers attachment to the patient.</p> <p>54% Parents attachment to pediatric institution.</p> <p>47% Patients ongoing active medical issues.</p> <p>73% of gastroenterologists reported personally providing self-care management skills, education or assessment with regard to transitioning.</p> <p>23% of providers used a structured standardized transition readiness assessment tool making this difficult to accurately assess health literacy in AYAs.</p> <p>Provider education alone has been shown to be ineffective.</p> <p>33% of respondents reported the ability to care for patients age 22-24, with 8% reported ability to care for 25-29.</p> <p>63% of respondents reported their practice had a policy in terms of "timing of transfer" most being flexible and others variable in terms of triggers (e.g., age, self-care skills, developmental milestones)</p>	Low response rate of respondents only 12% limiting the ability to generalize especially to private and community-based practices.	III High

Article #	Author(s) (Date)	Evidence Study/Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
6	Szalda et al. (2015)	Pilot QI study of a multi-disciplinary intervention navigation team (MINT) to accomplish goals relating to HCT and the Six Core Elements.	<p>Study from July 2015 to March 2017</p> <p>7 Divisions of pediatric subspecialties including gastroenterology</p> <p>Initiatives included to 1) develop system level innovations to increase capacity surrounding transitions from pediatric to adult care and 2) Perform consults for complex individual patient transfers.</p> <p>Needs assessment included Benchmarks for current activities set in place using Six Core Elements as a guide.</p> <p>MINT consult team consisted of 2 medical pediatric physicians, a nurse practitioner, social worker, youth community health worker, and a coordinator.</p> <p>MINT team consulted on complex patients to create and execute transfer plans.</p> <p>MINT team developed a transition policy template, EMR clinical decision support tools, a transfer note template, and a registry template.</p>	<p>7 Goals of the QI project where each participating division were given 6 aims aligned with the Six Core Elements to be implemented in their division. 1 being the increase of transition tools by providers.</p> <p>EMR-based transition tools were presented by MINT and a prompt was added into the EMR for providers to document “Counseling from Pediatric to Adult Care” onto the patient problem list with a flowsheet to score the TRAQ readiness assessment tool.</p> <p>All 7 divisions identified HCT champions within their division, used EMR-based tools for transition, developed a written policy, and held psychoeducational events for patients and families surrounding transition, created a transition registry, and identified adult provider counterparts in their specialty.</p> <p>MINT consult team received 80 referrals, 73 of which were deemed appropriate. After the 2-year period 33 were transferred to adult care, 23 in process, 18 were not completed.</p> <p>Successful transfer of 33 patients resulted in expanded capacity for new pediatric patients including 256 outpatient appointment, 25 inpatient admissions, 90 total hospital days and 55 ED visits.</p>	<p>Limited replicability due to large operational system wide changes.</p> <p>Longitudinal study is time and labor - intensive needing teams with protected time to engage in HCT activities.</p> <p>Needs institutional monetary level support as care coordination is not yet reimbursable through payers in the US.</p>	IV Good

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
7	Eluri, et al. (2017)	Cross-sectional survey	<p>Online survey of patients >13 and parents of patients with EoE/EGE diagnosed at < 25 years.</p> <p>N = 450 Parents = 245 Patients = 205 (13-25 years of age)</p> <p>Recruitment measures were gained through American Partnership for Eosinophilic Disorders and Campaign Urging Research for Eosinophilic Disease, email lists, and social media sites.</p> <p>STARx questionnaire was used to assess transition readiness.</p>	<p>Significant deficit in HCT knowledge and readiness scores for patients with EoE and EGE.</p> <p>78% of patients and 76% of parents reported having no prior knowledge of HCT.</p> <p>Parent reported readiness of their children was significantly lower than patient-reported readiness.</p> <p>Lower HCT readiness scores for patients with EOE vs. other chronic conditions.</p> <p>The preferred age for HCT in both patients and parents is 18 which is contrary to societal recommendation of 12 for initiation of HCT.</p>	<p>Factors that affect HCT were not assessed such as health insurance, race, access to resources, and education level.</p> <p>Subjects were recruited through support group and advocacy group websites which is likely a highly motivated population contributing to selection bias.</p> <p>The perceptions of providers were not obtained.</p>	III Good

Article #	Author(s) (Date)	Evidence Study/Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
8	Jensen et al. (2017)	Descriptive study; longitudinal	<p>n = 89 Age 16-23 years of age</p> <p>56% had rheumatic disease 21% had endocrine disease 23% had gastrointestinal disease</p> <p>Participants were assessed by TRAQ at baseline and providers were blinded to TRAQ results. They were followed over 3 years by telephone to determine if they had transfers to adult subspecialty appointment as defines as attending at least 1 adult subspecialty appointment.</p> <p>The time from baseline TRAQ measure at study entry to the date of the first adult provider appointment was examined.</p> <p>Single Pediatric Academic Specialty Center</p>	<p>TRAQ readiness tool was used to compare demographics and results against 3 subspecialties: Endocrine Rheumatology Gastroenterology</p> <p>45 % of respondents reported never having discussed transition to adult care with their pediatric provider.</p> <p>46% of respondents reported having never seen the pediatric specialty provider independent of the parent. Baseline TRAQ scores did not predict time to transition to adult care.</p> <p>Of note trend showing sooner time to transition with higher TRAQ scores.</p>	<p>Unable to generalize due to study conducted at a single center.</p> <p>Study did not address the quality of the transition process, cost, or patient satisfaction.</p> <p>Providers were blinded to the results which is in contradiction to how the tool was to be used over time with the results influencing the provider and patient collaboration.</p>	III High

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
9	Gray, Holbrook et al., (2015)	Qualitative focus group interviews	<p>6 focus groups consisted of 6-8 people to facilitate discussion. Two focus groups were conducted for each group of patients, parents, and medical personnel.</p> <p>Participants were recruited from Cincinnati Children's Hospital and other adult practices in the area.</p> <p>Participants included patients in pediatric and adult care settings, parents of patients, and both pediatric and adult providers of irritable bowel disease care.</p> <p>Focus group interviews focused on concerns and needs regarding transition to adult care.</p>	<p>Patient, parent, and healthcare professional perspectives of concerns, barriers, and recommendations to improve transition.</p> <p>Four themes emerged: Concerns about receiving a poorer quality of care in the adult setting is a barrier, High parental involvement serves as a barrier to patient self-management skills, Finances and insurance are a big concern, and Transfer to adult care represents a loss of valued relationships with pediatric providers.</p> <p>Suggestions to improve transition of care: Separate the patient and the parent for a part of the medical visit, Hold adolescents accountable for their care, and Teach the parents how to let go and support.</p>	<p>Single site study Low ability to generalize and selection bias</p>	III Good

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
10	Nehring et al. (2015)	<p>Systematic review of providers roles, understanding, and views pertaining to HCT</p> <p>Designed to answer the following questions: What is the state of HCT science pertaining to the role of providers involved with HCT? What research problems or questions have been investigated pertaining to providers involved with HCT? What evidence has been generated that can be applied to improve the HCT training or service competencies of evidence can be applied to the provision of HCT services for AEA-SHCN?</p>	<p>PRISMA guidelines were applied to 55 articles included from 2004-2013.</p> <p>26 studies in the US 27 studies in other countries 2 studies had samples from the US and other countries.</p> <p>All studies used descriptive designs using qualitative, mixed-methods, surveys, and semi-structured interviews.</p>	<p>Four themes were derived from the studies: Adult provider competency, Provider perspectives, Provider attitudes toward HCT, and HCT service models. Providers report the following barriers: Access to adult care, Self-management knowledge and skills needed for transition, Existence of transfer guidelines such as age and other criteria, and Service system capacity. Providers acknowledged the importance of HCT programs and that gaps remain in actual provision of HCT services. Providers identified other barriers to implementation of HCT. Attachment to the pediatric providers and child health settings, AYA treatment non-adherence and deficits in self-management skills, AYA condition instability to include cognitive, functions and psychological problems, Providers limited time for HCT services, Clinicians HCT knowledge gaps, and lack of understanding of HCT needs of adolescents and their parents, Excessive parental involvement in HCT, Difficulty terminating the relationships due to their attachments, Confusion about HCT role responsibilities, and Pediatric providers' beliefs or lack of confidence in adult provider's capability. Service system related barriers include: Lack of formalized transition plan, Lack of adult providers, Inadequate and or no reimbursement for transfer to adult care, Problems with accessing AYA medical records, and Problems with comprising an HCT team to provide HCT services.</p>	<p>Half of studies were from the US but difficulties in comparing health care delivery systems could not be made as Europe and other countries have different healthcare systems greatly impacting practice, and healthcare delivery. lessening the ability to generalize the findings.</p> <p>Majority of studies were convenience sampling methods. Not able to generalize.</p>	III Good

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
11	Gray, Resmini et al. (2015)	Quality improvement study	<p>Adolescents and young adults age 16-25 with irritable bowel disease, Crohn's disease, or ulcerative colitis.</p> <p>N = 195 from [REDACTED] where there was no formal transition plan in place.</p> <p>TRAQ scores were compared to institutional benchmark as well as to diagnosis, age, gender, disease activity.</p> <p>Most patients attending the gastroenterology clinic were from white and higher socioeconomic status.</p>	<p>TRAQ questionnaire used to determine mastery of skill set. TRAQ scores were compared to an institutional set benchmarks for readiness to transition scores of 90%.</p> <p>Benchmark of 90% was set by the transition task force team which was initiated to start a transition process within multiple chronic illnesses in a large academic institution.</p> <p>TRAQ scores were compared with the 90% skill mastery benchmark.</p> <p>5.6% of adolescents 18-25 years met the 90% mastery benchmark.</p> <p>The lowest scores were noted in healthcare utilization and advocacy.</p> <p>The 2 lowest scores were in health insurance.</p> <p>Greater skill mastery was noted when disease state is "quiescent"</p> <p>TRAQ tool gives providers easy and quick assessment of patient's readiness and should be used to understand patient needs as well as track institutional progress in transitional care programs</p> <p>Use of the TRAQ tool in clinics can help providers make discussion of HCT a routine practice, identify areas of needed skills, set goals, and track progress over time.</p>	<p>Convenience sampling where only patients that adhere to appointments were given the tool</p> <p>Parental perception as noted by the TRAQ tool were not evaluated.</p> <p>Most of the participants had quiescent disease activity.</p> <p>The predictable validity of the benchmark by the institution has not been established.</p>	IV Good

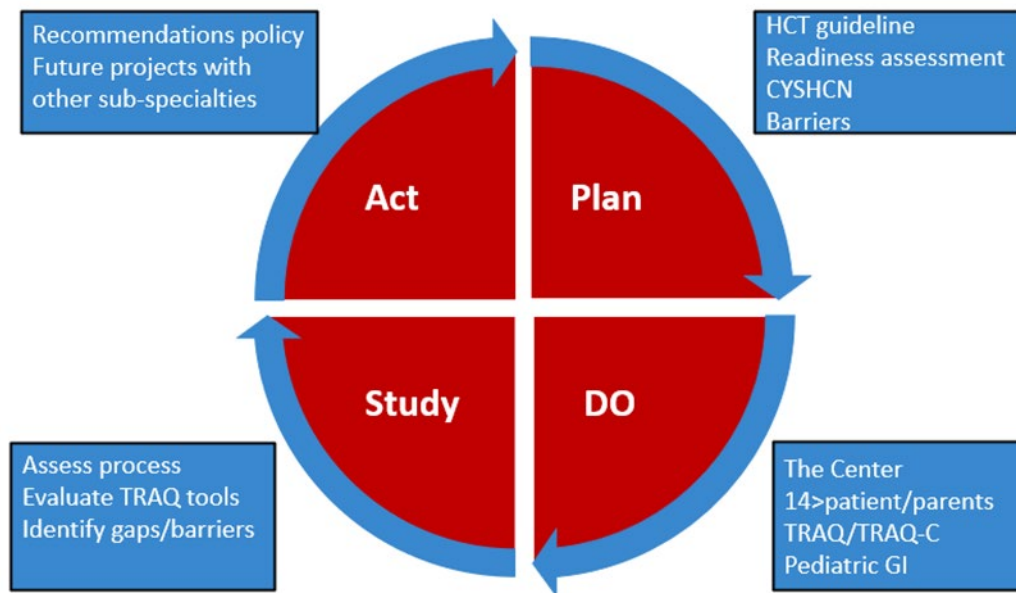
Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
12	Wiemann et al., (2015)	QI study of implementation of HCT planning tool into an EMR	<p>N = 21 providers N = 143 patients</p> <p>CYSHCN patient ages 16-25 years</p> <p>Conducted at a large children's hospital, [REDACTED]</p> <p>Implementation of a transition planning tool that incorporates 5 out of the 6 elements of HCT outlined in GotTransition.</p> <p>Aims were to: Increase provider use of a transition planning tool, Understand providers' satisfaction with the transition planning tool; and Enhance provider self-report of transition planning activities.</p>	<p>5 PDSA cycles were used to increase activities and provider use over a 35-month study period.</p> <p>Transition planning tool directly or indirectly addresses 5 of the 6 core elements of transition.</p>	Limited to 4 sub-specialty services within a single hospital.	IV Good

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
13	Shapiro et al. (2020)	Qualitative Narrative review of HCT in adolescents with irritable bowel disease to adult care. Systematic search strategy of Primary research studies that addressed at least 1 of the Six Core Elements. 50% of studies were conducted in the US.	38 studies met inclusion criteria ATAs with irritable bowel disease. Using the Six Core Elements of HCT as a guide, studies were reviewed in order to make recommendations to improve the process and identify areas for additional research within each core element.	Initiate discussions about transition as early as 12-14 years of age. Introduce the topic at diagnosis or once the disease is stable. Provide independent time with providers, educating patients about privacy/insurance changes, supporting gradual shifts in responsibility. Discuss differences in pediatric care and adult care. Introduce patients to their new doctors and clinics via joint clinics. Introduce adult providers to their new patient. In terms of element three Readiness Assessment-there is no “best” tool. Assess readiness at least once one year prior to transfer. Caregiver input for patient strengths and weaknesses.	Studies conducted in the US have not examined outcomes of transition success. Difficulty in conducting research over time in countries without national health systems i.e. United States	V High
14	Benson et al. (2018)	Cross-sectional survey study design was used to assess 16-26-year-old and their caregiver transition readiness.	16-26-year-old AYAs and their caregiver/parents attending one of 11 pediatric specialty clinics at a large Mid-Atlantic Military Treatment Facility N = 113 male N = 129 female N = 2 transgender STARx Readiness Assessment tool was given.	Before implementation, champions in each of the 11 pediatric specialties were identified to lead assessment, efforts and provided in person training on the purpose and procedure of the project. The primary investigator collected questionnaires from each clinic twice a week and provided face to face contact with staff for question and or concerns regarding administration and collection. The study ran over a 3-month time 60% of patients seen without caregiver were ready to transition. 38% of patients seen with a caregiver were ready to transition. Half of the older adolescent and young adults’ surveys possessed health care knowledge, attitudes, and behaviors needed for successful transition to adult care. Readiness assessment should be used at least every 6 months or at every visit if possible.	Eligible assessment not returned. All participants had the same US military insurance benefits which limits the ability to generalize to non-military populations.	III Good

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
15	Gray, Reed-Knight et al. (2018)	Multi-site quantitative comparison of patient, parent, provider perspectives on transition to adult care in irritable bowel disease	<p>Two major Children's hospital affiliated pediatric gastroenterology centers in the US- One located in the southeast and one in the mid-west.</p> <p>Patients, parents, and providers perspectives on what is most important in successful transition from pediatric to adult irritable bowel disease care.</p> <p>N =190 40% ~ patients >16 40% ~ parents 20% ~ providers</p> <p>Demographics of patients were mostly white, educated, and high socioeconomic groups.</p> <p>TRAQ form was used to quantify 1-5 the most important aspects of transition that are needed for success.</p>	<p>TRAQ tool used as a quantitative measure for perspectives of importance to HCT among patient, parents, and providers.</p> <p>Differences exist as to the perspective of stakeholders and what they perceive as most important in successful transition.</p> <p>Significant differences exist 46.5% of patients vs. 15% of provider's ranked "knowledge of health insurance coverage" as one of the top 5 for successful transition.</p> <p>Patients ranked items related to self-management skills as most important. Items such as "knowing how to call the doctor about unusual changes in health" 47.5% and "knowledge of health insurance coverage" 46.5% as the top two rankings.</p> <p>One item was exclusive to providers "answering questions asked by the medical staff" 45%, where this item did not make it to the top 5 in patient or parent categories.</p> <p>Inclusion of all stakeholders are important in developing transition programs.</p>	<p>Limited due to accessibility of stakeholders where only patients, parent, and providers were included.</p> <p>Due to differences found in these stakeholders as to what is most important in transition, then for future studies other stakeholders' perspectives should include, adult providers, post transfer patients and parents, hospital administrators, and insurers.</p>	III High

Article #	Author(s) (Date)	Evidence/Study Type	Sample, Sample Size, Setting	Findings That Help Answer the Evidence-based Practice Question	Limitations	Level
16	Bond et al. (2019)	Exploratory study; mixed methods	Piloted a structured developmental tool to assess transition readiness for youth with special needs. N = 28 pediatric health care providers comprised of 15 physicians, 6 nurses, and 7 social workers. Specialty clinics included endocrinology, hematology, and gastroenterology.	<p>Incorporating a structured tool into standard clinical practice should enhance the quality of the visit without increasing the length of the visit.</p> <p>89% of providers reported using a structured readiness assessment tool increased their knowledge of developmental milestones medical independence.</p> <p>Also assisted providers in shifting the focus to address patients at a younger age.</p> <p>92% of respondents reported that it was feasible to incorporate the tool into general clinical practice.</p>	<p>Limited sample size.</p> <p>Qualitative data were susceptible to bias as two tool developers were involved in data analysis and interpretation.</p>	V Good

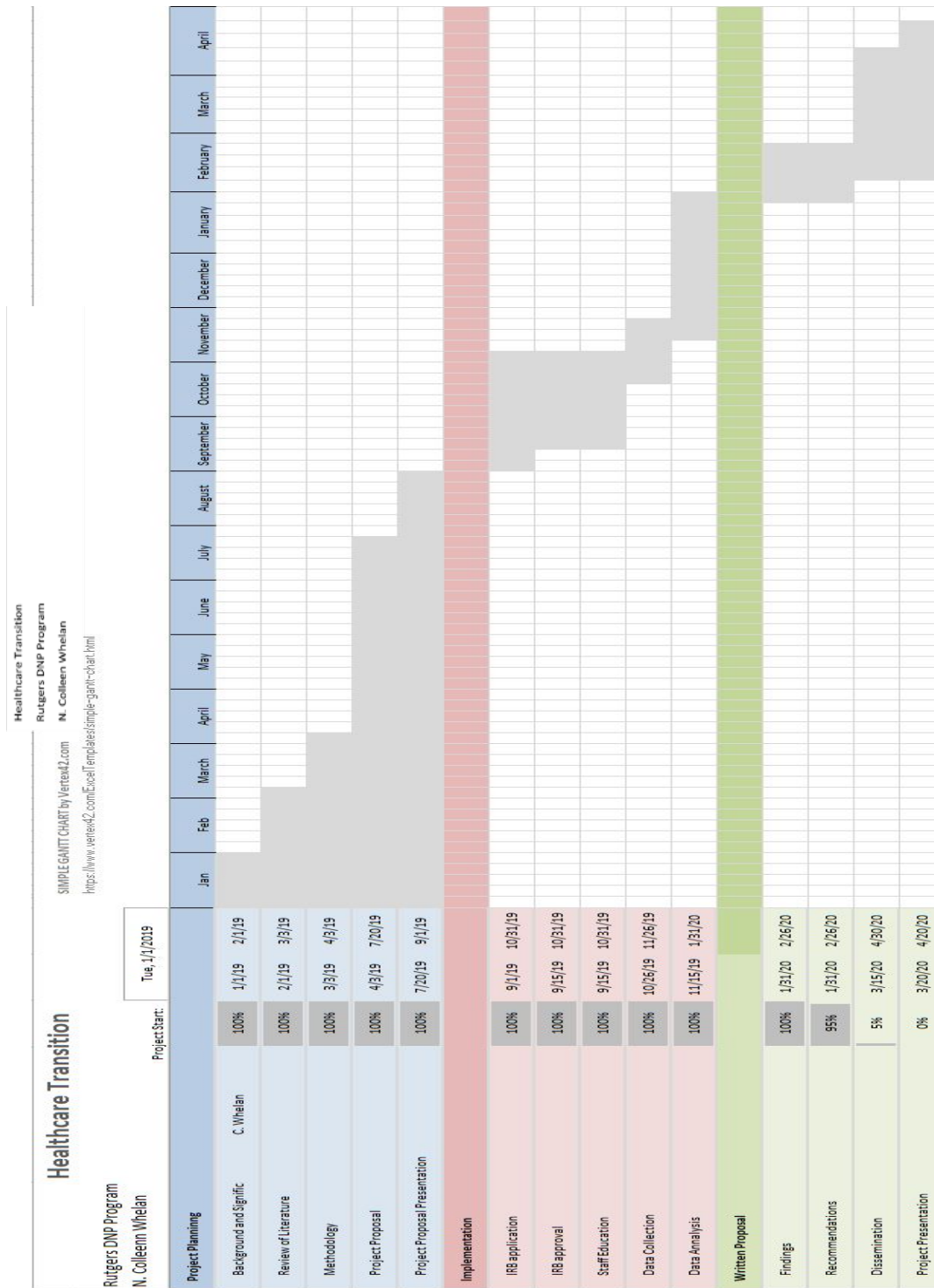
Note:
 AYA = Adolescent and Young Adults
 AAP = American Academy of Pediatrics
 AAFP = American Academy of Family Physicians
 ACP = American College of Physicians
 HCL = hypercholesterolemia
 HCT = healthcare transition
 TRAQ = Transition Readiness Assessment Questionnaire
 PRISMA = Preferred reporting items for systematic review and meta-analysis
 EMR = Electronic Medical Record
 EoE/EGE = Eosinophilic esophagitis/Eosinophilic gastroenteritis
 US = United States
 PDSA = Plan-Do-Study-Act
 AEA = Adolescents and Emerging Adults
 SHCN = Special Health care needs
 MINT = Multi-disciplinary navigation team

Appendix F**Theoretical Framework***Model for Improvement*

Adapted from Associates in Process Improvement (2009).

Appendix G

Project Timeline



Appendix H

Recruitment Poster

RUTGERS HEALTH



Are you ready for an adult care provider?

When is the right time for me?

Got Questions? Age 14 and up?

Ask about our survey!

Talk to your doctor today!

Appendix I
Recruitment Flyer

RUTGERS HEALTH

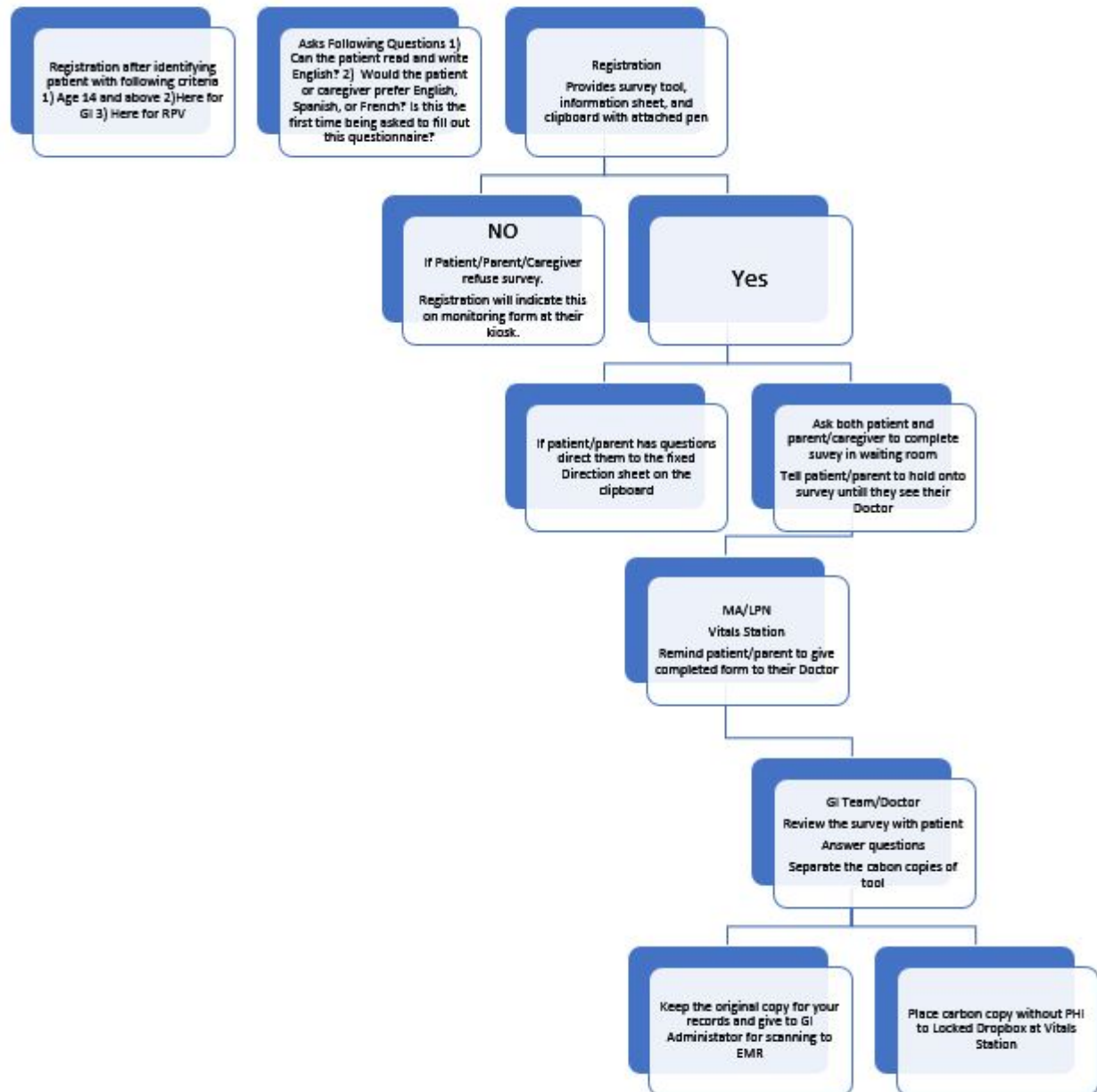


Are you ready for an adult care provider?
When is the right time for me?
Got Questions? Age 14 and up?
Ask about our survey!
Talk to your doctor today!

Appendix J

Workflow Diagram

RUTGERS HEALTH



Appendix K
Instruction Sheet

Information Sheet

Purpose: This project aims to improve how children move from a pediatric doctor to an adult doctor once they reach the age between 18-24. The TRAQ and TRAQ-C form will assist your doctors and nurses develop a plan of care to help you better understand your illness and the skills needed for a successful transfer to adult care in the future.

- Please complete the survey in the waiting room.
- Patients ≥ 14 please check off your age group and chronic health condition at the top of the page
- Parent/Caregiver please check the age group of your child and your child's chronic health condition
- Answer the questions that best describe your skill level in the following areas that are important for transition to an adult doctor.

Remember there are no right or wrong answers!

Your results will remain confidential and private!

Give the completed form to your doctor or dietician during your visit. All completed forms will be kept securely as per the regulations of Rutgers Health, Health Insurance Portability and Accountability Act Privacy and Protection Policy. Thank you!

Questions? Please direct those to your doctor/dietician, or you can call Colleen Whelan (Project Leader) at [REDACTED] or email at [REDACTED]

Appendix L**Budget***Budget: Summary of Projected Costs vs. Actual Costs*

Items	Projected Cost in Dollars	Actual Cost in Dollars
TRAQ forms with NCR forms (100)	50	80
TRAQ-C forms with NCR forms (100)	50	80
10 Clipboards and pens	50	25
Copying	50	10
Posters	50	15
2- Locked Survey Boxes	60	38
Refreshments for information sessions	100	250
Total	410	498

Appendix M

Contact Information



Purpose: This project aims to improve how children move from a pediatric doctor to an adult doctor once they reach the age of 18-24. The survey form will assist your doctors and nurses in developing a plan of care to help you better understand your illness and the skills needed for a successful transfer to adult care in the future.

Four Frequently Asked Questions

1) If I take this survey, does it mean I cannot see my doctor anymore?

Answer: No. You, your family, and your doctor will decide together when it is time for you to see an adult doctor.

2) What if I do not know how to do anything listed in this survey?

Answer: This is not a test. Skills towards independence take time to develop.

3) How can I find out more information about these questions?

Answer: You can visit www.gottransition.org; www.crohnscolitisfoundation.org;
www.gikids.org

4) Who can I ask if I have more questions?

Answer: Colleen Whelan is a pediatric nurse practitioner and the project leader. She can answer any questions. Please feel free to call or text her on her cell phone at [REDACTED] or email her at [REDACTED]