

Evaluation of Healthcare Transition Outcome Predictors for Adolescents/Young Adults Living  
with Chronic Medical Conditions

By

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Submitted to the graduate degree program in Psychology and the Graduate Faculty of the  
University of Kansas in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy.

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## Abstract

Medical advances have resulted in increased survival rates for patients with chronic, pediatric-onset medical conditions. As these patients require long-term medical follow-up, pediatric providers must help prepare them for the transition into the adult healthcare system. Transition preparation involves assessing and helping patients develop the relevant skills and knowledge that they need to manage their conditions independently and function effectively in the adult healthcare system. Both the development of psychometrically sound transition readiness measures and the identification of factors influencing transition success are needed to develop empirically-grounded healthcare transition models that can inform the delivery of transition services. The current study evaluated the psychometric properties of the Transitioning Preparedness Survey (TPS), a generic transition readiness measure, and attempted to explore potential predictors of transition success. Data collection included a retrospective medical record review of 152 patients with chronic medical conditions or a history of cancer who had received pediatric transition preparation services and a follow-up phone survey completed by nine patients who had transitioned out of pediatric care. Results supported the internal consistency of the TPS 18+ Version ( $n = 110$ , ordinal  $\alpha = 0.93$ ) and TPS 15-17 Version ( $n = 42$ , ordinal  $\alpha = 0.93$ ). The TPS 18+ Version's concurrent and convergent validity were supported by intercorrelations among its subscales, positive correlations with patient age, and higher scores among patients with lower risk of neurocognitive difficulties compared to patients at higher risk. Results also indicated limited support for the TPS 15-17 Version's concurrent and convergent validity. The small number of patients who provided transition outcome data precluded quantitative evaluation of the predictive validity of the TPS 18+ Version and the relationships of socio-demographic factors, medical characteristics, and indicators of engagement in pediatric services with transition

outcomes. Survey completers' responses suggested that health insurance coverage in adulthood, parental support, self-perceived transition readiness, and self-advocacy skills may be additional potential predictors of transition outcomes to investigate in future studies. The TPS measures showed promise as clinically useful measures of transition readiness. Recommendations were provided for continued development of the TPS and of a model of empirically determined predictors of transition outcomes.

*Keywords:* healthcare transition, pediatric, chronic medical condition

## Acknowledgements

I thank my dissertation committee members for their support of this project and their contributions to multiple aspects of my graduate training. Specifically, I thank Dr. Michael Rapoff for encouraging me to collaborate with our colleagues at Children's Mercy Hospital (CMH) on this project, for mentoring me as I completed each stage of this project, and for facilitating my development as a researcher and clinician over the course of my graduate studies. I also thank Dr. Eve-Lynn Nelson for connecting me with the clinicians at CMH involved in transition services and for creating an opportunity for me to gain experience in providing clinical services within the KUMC Survivorship Transition Clinic. I thank Dr. Sarah Kirk for imparting the skills, providing the guidance, and sharing the encouragement I needed to pursue a career in pediatric psychology. I also thank Dr. Amber Watts, Dr. Tamara Baker, Dr. Tracey LaPierre, and Dr. Jarron Saint Onge for your enthusiasm for this project and your insightful critiques and comments, which have shaped not only this project but also the program of research I wish to pursue throughout my career.

I also deeply appreciate the generous support of time, resources, and help with this project that many at CMH have offered. Specifically, I thank Dr. Joy Fulbright, Dr. Ann Modrcin, and Terri Hickam for welcoming my proposal for this study, connecting me with all the participating clinics, and guiding me through the data collection process. I thank Wendy Hein, Dr. Diane Kennedy, and Kyla Alsman for answering all of my questions over the course of the project and for all the practical help provided. I also wish to thank all the clinicians in the Survive and Thrive, Muscle Nerve, Spinal Defects, EDICS, and Rheumatology Transition Clinic for the compassionate care you have provided to so many adolescents and young adults, which has enabled them to pursue their dreams and has made this project possible. I thank the patients

seen in these clinics and their families, as you have inspired me with your resilience and courage. I especially wish to thank the young adults who shared the latest part of your medical journeys with me.

I thank my fellow graduate students who have also supported me through the completion of my research and my studies at the University of Kansas. I thank Ali Calkins for your generous spirit and your help with reliability coding and obtaining research consents for this project. Along with Ali, I thank Dr. Catrina Lootens and Dr. Alex Williams for making the Rapoff lab such a wonderful environment for conducting research through your collaborative attitudes, honest critiques, and genuine encouragement. Finally, I thank my husband, Dr. Ty Owens, for your companionship and support in facing all the challenges of this project and of establishing our life together and our careers.

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## **Introduction**

As medical advances improve survival rates of patients with chronic, pediatric-onset medical conditions, many of these individuals will eventually face the transition from the pediatric healthcare setting into the adult-care system. This healthcare transition (HCT) is a complex process involving the assumption of new roles for the adolescent/young adult (AYA) patient, family members, pediatric healthcare team members, and adult healthcare team members. One focus of HCT research involves the AYA patients' readiness for transition – their development of skills that will aid in the HCT process and support the patients' successful functioning in adult healthcare settings. In this document, I present an overview of HCT and transition readiness (TR), review models of HCT to provide a theoretical framework for the discussion of factors potentially influencing HCT outcomes, discuss definitions and empirical correlates of HCT success, and review currently available TR assessment tools. I also present the results of a study conducted to test the psychometric properties of a TR measure used in multiple transition programs within a local pediatric hospital and the TR measure's ability to predict HCT success; and to test the relative contributions of socio-demographic factors, medical characteristics, indicators of engagement in pediatric and transition preparation services, and TR in predicting HCT success.

### **Healthcare Transition: Definition, Barriers, and Transition Readiness**

Clinical and research attention to the HCT of AYAs with chronic, pediatric-onset medical conditions has increased over the last few decades. In the United States, about 15.1% of children and adolescents seventeen years of age and younger have special healthcare needs (including chronic medical conditions); and, due to the continual improvement of medical interventions, over 90% are expected to survive into adulthood (Data Resource Center for Child & Adolescent

Health, 2009/10). This survival rate translates into over 500,000 of these patients becoming adults each year (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002). Both the increased number of transitioning patients and the increased severity of the conditions with which these patients live present challenges for the pediatric and adult healthcare systems to meet these patients' needs for adequate HCT preparation and for access to appropriate long-term care in adulthood. Ideally, the HCT would be a "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems," in accordance with the Society for Adolescent Medicine's definition of HCT (Blum et al., 1993, p. 570). Such a transition would support the provision of uninterrupted and developmentally appropriate care for AYAs so that the patients enjoy optimal health and the attainment of their maximum potential (American Academy of Pediatrics et al., 2002; Rosen, Blum, Britto, Sawyer, & Siegel, 2003). The definition and aims of HCT emphasize that HCT is a process, requiring deliberate preparation and support of the patient before the event of transfer to adult care, as well as during and after the transfer.

Unfortunately, many patients face substantial barriers to a successful HCT. These barriers occur at the healthcare system level and at the level of the individuals involved in transition (i.e., the pediatric and adult healthcare providers, the parents and caretakers, and the AYA patient). HCT barriers include limited or no access to adult primary care and specialist providers sufficiently trained in the long-term care of patients with pediatric-onset conditions; gaps or changes in health insurance coverage; inadequate coordination and communication between pediatric and adult healthcare providers; lack of time in pediatric clinic appointments to address transition-related issues or lack of structure in transition programs; pediatric healthcare

providers' and parents' reluctance to let go of AYA patients; patients' reluctance to leave pediatric healthcare providers; patients' and family members' anxiety about life outside of pediatric care; and deficiencies in AYA patients' disease-related knowledge, ability to manage their healthcare, and ability to function independently in the adult healthcare system (Barendse et al., 2010; Clarizia et al., 2009; Eshelman-Kent et al., 2011; Fox, 2002; Griffin et al., 2013; Jordan, Swerdlow, & Coates, 2013; Rutishauser et al., 2011).

AYA survivors of childhood cancers experience similar and additional barriers to their transition into adult-centered survivorship care, which involves regular risk-based screening for cancer recurrence, secondary malignancies, and late effects of cancer treatments received (Henderson, Friedman, & Meadows, 2010). Unique barriers for survivors include the association of survivorship care with their families' past traumatic experiences of active cancer treatment and with a sense of stigma due to others' misperceptions of survivors' cancer experience (Casillas et al., 2010); survivors' limited knowledge of their cancer treatment and risks for late effects, particularly if they underwent treatment very early in life (Kadan-Lottick et al., 2002); cognitive and developmental delays increasing some survivors' dependency on families and pediatric healthcare providers (Butler & Haser, 2006); and differences in survivors' and oncologists' expectations (Cheung, Neville, Cameron, Cook, & Earle, 2009), as well as differences between oncologists' and primary care physicians' preferences (Cheung et al., 2013), regarding oncologists' and primary care physicians' responsibilities in providing survivorship care.

Such barriers contribute to the increased risk for AYAs' unsuccessful transition to needed follow-up care with adult healthcare providers (Nathan et al., 2008; Reid et al., 2004), AYAs' struggling with adherence to medical regimens (Bollegala, Brill, & Marshall, 2013; Pai &

Ostendorf, 2011), and AYAs' experiencing disease-related complications. Examples of severe disease complications include increased rates of organ rejection and death among AYA transplant recipients, likely due to medication nonadherence (Shemesh, Annunziato, Arnon, Miloh, & Kerkar, 2010), increased use of emergency department services and rate of death among AYAs with sickle cell disease (Griffin et al., 2013), and earlier onset of diabetes complications and premature death in adults with type 1 diabetes (Garvey, Markowitz, & Laffel, 2012). In light of the serious consequences of failed or poorly conducted transition to adult healthcare, the HCT process must include components that promote AYAs' access to primary and specialty healthcare providers who are equipped to treat adults living with pediatric-onset conditions and that cultivate the skills AYAs will need to manage their health independently and function effectively in the adult healthcare context.

Essential to the improvement of the HCT process is the pre-transfer assessment of the patient and family to determine what support and resources they will need through the transition process and their readiness for transition. The concept of transition readiness (TR) has been defined as a set of "indicators that patients and those in their support system (e.g., parents and providers) can begin, continue, and finish the transition process from child-centered to adult-oriented healthcare, through the event of transfer" (Schwartz et al., 2013, p. 940). Assessment of TR could lead to the identification of individuals at elevated risk for an unsuccessful transition outcome and to the specification of TR indicators that would be potential targets for individualized transition preparation interventions. Additionally, TR assessment results could provide a more flexible, idiographic, and accurate alternative to a rigid age criterion for basing decisions about the timing of transfer (Fredericks et al., 2010).

## **Models of Healthcare Transition and the Transition Readiness Construct**

In their systematic review, While and colleagues (2004) identify four models of transition differing on definitions of continuity and the specific needs of groups of patients, their families, and healthcare providers. The Sequential Transition Model and the Developmental Transition Model are particularly relevant to the concept of TR as they take into account the changing needs of and demands placed on the AYA patient over the course of the transition process. These two models describe the roles of the healthcare teams as including the provision of services that differ from child healthcare services in that the teams encourage the AYA to practice skills and gain knowledge about his or her condition in preparation for entering adult care (Sequential model) or assist the AYA in acquiring these skills and knowledge (Developmental model). These models also recognize the need for family members to adjust their roles in caring for their AYA to complement the patients' assumption of the adult patient role. In light of these models, TR can be understood as encompassing both the process by which the AYA patient gains self-care skills and knowledge relevant to functioning in the adult-care system and the process by which family members adjust to the patient's increasing autonomy.

Treadwell and colleagues' (2011) application of Bronfenbrenner's biosocial-ecological systems model (Bronfenbrenner & Ceci, 1994) to HCT emphasizes the larger context of transition to adulthood. This context encompasses the AYA's navigation of changes in his or her microsystem (e.g., family, school, spiritual community, peers, and healthcare providers); mesosystem (i.e., interactions among the individual microsystems); exosystem (e.g., regional community, mass media, political landscape, industry, and social services); and macrosystem (e.g., societal/cultural influences). Implications include acknowledging that an AYA's readiness for HCT both influences and is influenced by the patient's general ability to cope with other



stage-of-life changes. Thus, an AYA's approach to educational/occupational transition, changes in familial relationships and roles, and social transitions are likely relevant to the understanding of his or her HCT readiness.

Another model influenced by Bronfenbrenner's model is the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART; Schwartz et al., 2013). The SMART framework categorizes TR indicators into two groups: preexisting factors that are less amenable to intervention (e.g., socio-demographic/cultural, access/insurance, medical status/risk, and neurocognitive function/intelligence) and modifiable factors (e.g., knowledge, skills/self-efficacy, beliefs/expectations, goals/motivation, relationships/communication, psychosocial/emotional, and developmental maturity). The SMART emphasizes that multiple stakeholders' (i.e., patient, parents, and healthcare providers) perspectives and experiences of the modifiable factors influence transition outcomes.

Complementing the broader, theory-driven conceptualizations of HCT in the models discussed so far, a framework for HCT research described by the Health Care Transition Research Consortium (Betz et al., 2014) represents an attempt to outline the domains and specific variables identified in the literature that may affect HCT outcomes. The HCT Research Consortium is an international and interdisciplinary group composed of healthcare professionals in a variety of disciplines as well as AYAs and their family members. The leaders of the Consortium are faculty members at the University of North Carolina, the University of Southern California, the University of California San Francisco, and the University of Florida. The Consortium suggests that its model serve as a guide for research and clinical efforts aimed at measuring and empirically testing the relationships that the proposed variables, mediators, and moderators may have with HCT outcomes. The model specifies four domains influencing HCT:

the individual domain (encompassing demographic, disease, developmental competencies, personality, social participation, health-related self-management, and self-advocacy characteristics of the AYA); the family/social support domain (family support for the AYA, social support network and environment); the healthcare system domain (competencies and services of the pediatric care system, competencies and services of the adult care system, health insurance access and payment/reimbursement structures, patient-provider relationship); and the environment domain (educational systems, community services and supports, health policy and legal system standards and resources).

Within the individual domain, there has been a focus on self-management and self-advocacy competencies as targets of transition preparation interventions. Self-management competencies include regimen adherence, health literacy, knowledge of specific disease/condition, health-promoting behaviors, avoidance of high-risk behaviors, adherence to health promotion screening guidelines, independence, and responsibility-taking. Self-advocacy competencies include the patient's ability to communicate needs to healthcare providers, ability to advocate for needed services, ability to organize and access resources needed for healthcare, and awareness of personal rights and protections. In the family domain, family advocacy skills, health literacy, parent-child shared decision making, and family support for the AYA's self-advocacy may also represent targets of intervention.

These theoretical frameworks of HCT emphasize that the TR construct encompasses not only the AYA patient's acquisition of competencies (e.g., healthcare self-management, self-advocacy, health-related knowledge, interpersonal/communication skills) but also the successful changes in the roles of caregivers and healthcare providers as well as the patient's navigation of other, concurrent life transitions. As emphasized by Betz and colleagues (2014), HCT is a

complex process involving multiple life domains, and there is a need for empirical studies to determine how individual variables relate to transition outcomes and how these relationships are mediated and moderated. Early progress towards this goal requires the specification of transition outcomes and the identification of direct predictors of transition outcomes.

### **Transition Outcomes and Correlates**

**Definitions and rates of successful transition.** Within the transition literature, there are no universally accepted definitions of successful and unsuccessful transition outcomes (Tsybina et al., 2012). Thus, successful and unsuccessful transition outcomes have been operationalized in a variety of ways, which has likely influenced the range in transfer estimates among national surveys examining primary care transition and regional studies examining specialty care transition for specific diagnostic groups. The 2007 Survey of Adult Transition and Health (SATH), sponsored by the Maternal and Child Health Bureau (U.S. Department of Health and Human Services, Health Resources and Services Administration), was a national follow-back study to the 2001 National Survey of Children with Special Health Care Needs examining transition to adult primary care. In their analyses of the SATH data, Oswald and colleagues (2013) defined successful transition as (a) the young adult patient has a usual healthcare source, usual routine preventive care source, or a personal doctor or nurse; (b) the patient's doctor does not only treat children, teens, or young adults; (c) the patient has had continuous health insurance coverage for the past 12 months; (d) the patient's health insurance benefits meet the patient's needs; (e) the patient has had at least one preventive healthcare visit in the last 12 months; (f) the patient was satisfied with health services; and (g) the patient had not delayed or foregone needed healthcare in the last 12 months. SATH results indicated that only 21.6% of 1,865 young adults

with special healthcare needs met all the criteria for successful transition. Rates for meeting at least one transition criterion ranged from 62.6% (criterion (c)) to 89.1% (criterion (a)).

The rates of successful transition have been studied in several condition-specific patient groups. Reid and colleagues (2004) examined the rate at which patients with complex congenital heart disease successfully transferred from the largest pediatric cardiac center in Canada (the Hospital for Sick Children in Toronto) to adult care through one of fifteen specialized adult congenital heart disease treatment centers within the Canadian Adult Congenital Heart (CACH) Network. They defined successful transfer as a patient's attendance of at least one appointment of any type (clinic, echocardiogram, cardiac catheterization, or cardiac surgery) at a CACH center. Reid and colleagues obtained information about transfer outcomes through surveys and phone calls to the patients with congenital heart disease and through examination of the CACH centers' appointment databases. Of the 360 patients included in this study, only 47% successfully transferred their care to a CACH center and 2.8% had registered at a CACH center but had not yet attended an appointment. About half of the young adult patients had failed to transfer their care to a CACH center, and 27% of all patients reported that they had not seen any cardiologist (pediatric, general adult cardiologist, or adult cardiologist specializing in the care of patients with congenital heart disease) since the age of eighteen years.

In Andemariam and colleagues' (2014) study of patients with sickle cell disease, they defined successful transfer as a patient's attendance of at least one outpatient visit at the adult sickle cell center to which the patient had been referred following the patient's discharge from the pediatric sickle cell center. Of the 47 patients who participated in a transition program involving combined clinics (both pediatric and adult sickle cell disease healthcare providers in attendance), 68% successfully transferred their care to the adult sickle cell center. Although

continual adult care was not part of the study's definition of successful transfer, the authors noted that all successfully transferred patients did establish continual, ongoing, and comprehensive care.

By Reid and colleagues' (2004) and Andemariam and colleagues' (2014) definitions of successful transfer, patients who experienced discontinuity in specialty care services but who eventually sought these services were considered successfully transferred. In contrast, Hazel and colleagues' (2010) definition accounted for continuity in adult-care services, which is an important aspect of successful HCT. Hazel and colleagues studied the experiences of young adults with juvenile idiopathic arthritis during the first two years post-transfer, and they defined unsuccessful transfer as a patient's failure to contact an adult rheumatologist within those first two years post-transfer *or* failure to continue to follow-up with the adult rheumatologist (i.e., after the last scheduled adult rheumatology appointment, the patient did not contact the adult rheumatologist within a one-year period to schedule a follow-up appointment). Of the 100 patients studied, 52 were considered to have unsuccessfully transferred to adult specialty care, with 17 making no contact with the referred adult rheumatologist and 35 being lost to follow-up within the two-year post-transfer period.

The focus of long-term follow-up care on preventing and screening for cancer recurrence, secondary malignancies, and late effects based on childhood cancer survivors' individual risk profiles complicates the definition of successful transition to adult survivorship care. Though the Childhood Cancer Survivor Study did not explicitly focus on the transition outcomes of young adult survivors of childhood cancers, this study of fifteen North American institutions' efforts to characterize and track health outcomes of over 14,000 survivors (Robison et al., 2002) included documentation of the types of medical services that the adult survivors used (Nathan et al.,

2008). The healthcare use survey completed by 11,114 survivors (mean age in the early 30s) indicated that, in the two years prior to the survey, 11.2% of survivors did not receive any kind of medical care, 57.3% received general medical care services (at least one medical visit for care unrelated to their history of cancer), 13.7% received general survivor-focused care (at least one medical visit involving care related to their history of cancer without risk-based screening or discussion of risk reduction strategies), and 17.8% received risk-based, survivor-focused care (at least one medical visit involving risk-based screening or discussion of risk reduction strategies in light of cancer history). While a large majority of survivors in this study had received adult-oriented medical care, only a little over 30% of survivors were receiving care addressing some of the specific needs associated with cancer survivorship.

**Correlates of transition outcome.** In only the last decade, researchers have begun studying correlates of transition outcomes to identify potential facilitators of successful transition and risk factors for unsuccessful transition. A small number of studies have found several socio-demographic factors, medical characteristics, and other factors associated with transition outcomes. These transition outcome correlates are reviewed below along with correlates of patients' receipt of transition preparation services from pediatric healthcare providers, as the latter may also affect transition outcomes.

***Socio-demographic factors associated with transition outcomes.*** Results of national surveys examining transition outcomes or the receipt of transition preparation services from pediatric healthcare providers (McManus et al., 2013; Oswald et al., 2013; Richmond, Tran, & Berry, 2012), of a single institution's study of transition in patients with juvenile idiopathic arthritis (Hazel, Zhang, Duffy, & Campillo, 2010), and of studies describing adolescent and adult cancer survivors' engagement in survivorship care (Barakat, Schwartz, Szabo, Hussey, & Bunin,

2012; Nathan et al., 2008) generally indicated that females are more likely to experience successful transition outcomes compared to males. However, in a study of 258 young adults with type 1 diabetes, female gender was a risk factor for experiencing a gap exceeding six months between their last pediatric appointment and first adult-care appointment (Garvey, Wolpert, et al., 2012). In single institutions' studies of patients with congenital heart disease (Reid et al., 2004) and sickle cell disease (Andemariam et al., 2014), no gender differences were found.

Racial and ethnic disparities in the receipt of transition preparation services were noted in national surveys of patients with special healthcare needs (McManus et al., 2013; Richmond et al., 2012). Specifically, non-Hispanic Black and Hispanic adolescents were less likely to receive these services compared to non-Hispanic White or multiracial adolescents, even when all adolescents received care within a medical home. Among adult cancer survivors who were engaged in some type of adult-oriented medical care, Black survivors were less likely to receive survivorship-specific medical services; among survivors receiving survivorship services, survivors in the racial category of "other" (i.e., not White, not Hispanic, and not Black) were more likely than White survivors to receive risk-based survivorship care (Nathan et al., 2008). Non-White adolescent cancer survivors were more likely to miss survivorship follow-up appointments (Barakat et al., 2012). Race and ethnicity were not associated with transition outcomes in a sample of patients with sickle cell disease (Andemariam et al., 2014) and a sample of patients with diabetes (Garvey, Wolpert, et al., 2012). In these two studies, the high representation of one racial group (87% of the sickle cell disease sample was Black; 92% of the diabetes sample was White) may have affected ability to detect racial differences.

In the majority of non-Canadian studies, adequate insurance coverage of healthcare services was associated with positive transition outcomes or transition-related factors (McManus et al., 2013; Nathan et al., 2008; Oswald et al., 2013; Richmond et al., 2012). Having public insurance (e.g., Medicaid) was associated with a greater number of missed survivorship appointments among adolescent cancer survivors (Barakat et al., 2012). Insurance type (private vs. public) was not associated with transition outcomes among patients with sickle cell disease (Andemariam et al., 2014) and patients with diabetes (Garvey, Wolpert, et al., 2012), which may be attributable to sample-specific factors (e.g., many of the patients with sickle cell disease had public insurance, which in that area, covered transportation to appointments; 90% of the patients with diabetes had private insurance).

Higher household income and higher levels of parental/household member educational achievement were associated with successful transition (Oswald et al., 2013), receipt of transition-related services (McManus et al., 2013; Richmond et al., 2012), and access to general medical care (Nathan et al., 2008). The patients' level of educational achievement was associated with continuity of care for patients with type 1 diabetes (patients without college degrees were more likely to have experienced a six-month or longer gap between pediatric and adult medical services; Garvey, Wolpert, et al., 2012) but was not associated with transition outcomes for patients with congenital heart disease (Reid et al., 2004) or juvenile idiopathic arthritis (Hazel, Zhang, Duffy, & Campillo, 2010).

Closer geographical proximity to adult specialty clinics or cancer survivorship clinic was associated with successful transition (Andemariam et al., 2014; Barakat et al., 2012; Reid et al., 2004). Patients with congenital heart disease who were older at the time of their last pediatric appointment were more likely to transition successfully to adult care (Reid et al., 2004), and



pediatric healthcare providers were more likely to delivery transition preparation services to older adolescents (McManus et al., 2013). However, patients with sickle cell disease who began participation in a transition preparation program when they were twenty-one years or older were less likely to transition successfully (Andemariam et al., 2014). The inconsistencies in the relationship between age at last pediatric appointment and transition outcome may be influenced by different clinics' policies on when transition preparation services are provided and factors that may delay transition for some patients (e.g., cognitive impairments, achievement of medical stability). Patient engagement in adult healthcare may also change over the course of adulthood. Adult survivors of childhood cancer who were older in age were less likely to have engaged recently in survivorship-specific follow-up care compared to general medical care (Nathan et al., 2008).

*Medical characteristics associated with transition outcomes.* The medical characteristics examined for association with transition outcomes varied greatly across studies due to the condition-specific nature of the medical characteristics of interest. Relationships between medical characteristics and transition may also vary across medical condition groups. Results of national surveys indicated that adolescent patients experiencing less impact of their condition on functioning were more likely to receive transition preparation services from pediatric providers (McManus et al., 2013; Richmond et al., 2012). In contrast, patients with congenital heart disease experiencing greater impairment (i.e., disease-related symptoms, activity restrictions, poorer physical functioning, medical comorbidity), patients with juvenile idiopathic arthritis experiencing greater pre-transfer disease severity (i.e., higher active joint count), and adult survivors of childhood cancer with a history of cancer relapse or experiencing worse health (i.e., moderate-to-extreme cancer-related pain, poor physical health, serious medical morbidity)

were the ones more likely to transition to adult or survivorship care (Barakat et al., 2012; Hazel, Zhang, Duffy, & Campillo, 2010; Nathan et al., 2008; Reid et al., 2004). This contrast may reflect pediatric providers' focus on preparing patients whose symptoms are better controlled for transition and patients with greater condition-related impairment being more motivated to seek adult medical care.

Specific medical treatment and diagnostic factors, clinic attendance, and symptom management were associated with transition. A greater number of pediatric cardiovascular surgeries was associated with successful transition for patients with congenital heart disease (Reid et al., 2004). History of radiation treatment for cancer was associated with engagement in risk-based survivorship care (Nathan et al., 2008), and history of a liquid tumor was associated with stronger engagement in adolescent survivorship care (Barakat et al., 2012). Having a less severe form of sickle cell disease (genotype of SC or S $\beta$ +) and having no need for chronic transfusion were associated with poorer transition outcomes (Andemariam et al., 2014). Higher frequency of cardiac or diabetes appointments during adolescence and better pre-transfer glycemic control in adolescents with diabetes were associated with later success in transition (Garvey, Wolpert, et al., 2012; Reid et al., 2004).

*Other factors associated with transition outcomes.* Patients' experience of emotional and behavioral difficulties, engagement in the pediatric healthcare system, reasons for transition initiation, and transition preparedness appeared to affect transition outcomes. The association between emotional and behavioral difficulties and transition outcomes varied according to type of difficulty. Patients whose special healthcare need involved psychological or developmental conditions (McManus et al., 2013) and patients with congenital heart disease engaging in significant substance use (Reid et al., 2004) were less likely to experience positive transition

outcomes. However, anxiety in cancer survivors may have motivated engagement with risk-based survivorship care in adulthood (Nathan et al., 2008).

Patients who had received all routine preventive care throughout their childhood and who had pediatric healthcare providers who listened carefully when communicating with families were more likely to transition successfully (Oswald et al., 2013). Transition precipitated by geographical relocation tended to result in a six-month or greater delay in engagement with adult-care services for patients with diabetes (Garvey, Wolpert, et al., 2012). Patients' attendance of pediatric medical appointments without their parents, beliefs about the need for regular follow-up in adulthood with specialists having expertise in their condition, having a recommendation from their pediatric provider to a specific adult-care provider, and subjective report of feeling mostly or completely prepared for transition were associated with positive transition outcomes in patients with diabetes or congenital heart disease (Garvey, Wolpert, et al., 2012; Reid et al., 2004).

**Summary.** The socio-demographic factors of gender, race/ethnicity, insurance coverage, household income, parental/household member educational achievement, and proximity to adult care clinics tend to be consistently associated with transition-related outcomes. The relationship between transition outcome and the effect of patients' medical conditions on their functioning requires clarification. History of more intense treatment and patterns of engagement in primary and specialty healthcare during childhood or adolescence tend to be associated with transition success. Patients' ratings of TR, beliefs about post-transfer care, and practice of some TR skills appear to be associated with transition success, but require further investigation with more comprehensive measures of TR.

## **Reviews and Evaluations of Currently Available Transition Readiness Measures**

**Published reviews.** Two systematic reviews published in the *Journal of Pediatric Psychology* (Schwartz et al., 2014) and in *BioMed Central Pediatrics* (Zhang, Ho, & Kennedy, 2014) identified and evaluated available TR measures. Schwartz and her colleagues (2014) identified four generic and six medical condition-specific TR measures for which psychometric data had been published in peer-reviewed journals. The generic TR measures were the California Healthy and Ready to Work Tool (Betz, 1998, 2000; Betz, Redcay, & Tan, 2003), the Self-Management Skills Assessment Guide (Williams et al., 2010), the Transition Readiness Assessment Questionnaire 4.1 (Sawicki et al., 2011), and the UNC TRxANSITION Scale (Ferris et al., 2012). Among the identified condition-specific TR measures, the Cystic Fibrosis Health Care Transition Readiness Scale (Dudman, Rapley, & Wilson, 2011) and the Readiness Questionnaire (Cappelli, MacDonald, & McGrath, 1989) had been developed for patients with cystic fibrosis; the Readiness for Transition Questionnaire (Gilleland, Amaral, Mee, & Blount, 2012) for kidney transplant recipients, and the Transition Readiness Survey: Adolescent/Young Adult and Parent versions (Fredericks et al., 2010) for liver transplant recipients; the Transition Readiness Questionnaire for patients with human immunodeficiency virus (HIV); and the Sickle Cell Transfer Questionnaire (Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004; Telfair, Myers, & Drezner, 1994) for patients with sickle cell disease.

Schwartz and colleagues' (2014) evaluation determined that all ten TR measures met the evidence-based assessment (EBA) criteria (Cohen et al., 2008) for "promising assessments." Cohen and colleagues (2008) had defined "promising assessments" as measures that had "been presented in at least one peer-reviewed article" with "sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon

request)” and with “validity and reliability information presented in either vague terms (e.g., no statistics presented) or moderate values” (p. 913). The “promising assessment” category represented the lowest category within the EBA system for classifying measures. Higher categories were “approaching well-established,” indicating that at least two published articles presented moderate or vague support for an assessment tool’s psychometric properties, and “well-established,” indicating that at least two articles published by at least two different research groups presented detailed and strong statistical support for the assessment tool’s psychometric properties. The reviewers noted that the development processes of some of the TR measures were strengthened by theoretical grounding or use of mixed methods participatory approaches. They also reported that approaches to validity testing and support for the TR measures’ validity were varied and that factor analysis had been conducted on only two measures to determine the unitary or multifaceted nature of the measured construct. Based on their review, Schwartz and colleagues (2014) urged further testing of currently available measures as well as the continued development of new TR measures. They recommended that TR measure developers test the measures’ psychometric properties using appropriately sized, diverse samples; that developers ground measures in specific theories and involve multiple stakeholder perspectives throughout the development and assessment phases; that developers consider the strengths and weakness of generic compared to condition-specific measures; and that developers assess the TR measures’ ability to inform targets of transition preparation interventions and to identify patients’ response to these interventions.

Zhang and colleagues’ (2014) systematic review identified three generic and seven condition-specific TR measures. The reviewers evaluated the methodological quality of the TR measures’ psychometric properties and validation studies using Terwee’s standardized checklist

(Terwee et al., 2007). Terwee and colleagues' (2007) checklist provided detailed criteria for making ratings (positive, indeterminate, negative, or no information) of the quality of health status questionnaires within the domains of content validity, internal consistency, criterion validity, construct validity, reproducibility, responsiveness, floor and ceiling effects, and interpretability. The reader is referred to Terwee and colleagues' original article for the specific rating criteria. Seven measures identified in Zhang and colleagues' review overlapped with TR measures discussed in Schwartz and colleagues' (2014) review: the Transition Readiness Assessment Questionnaire (generic), UNC TRxANSITION Scale (generic), Self-Management Skills Assessment Guide (generic), Readiness Questionnaire (cystic fibrosis), Readiness for Transition Questionnaire (kidney transplant), Transition Readiness Survey (liver transplant), and Transition Readiness Questionnaire (HIV). Unique measures identified in Zhang and colleagues' (2014) review were the Self-Care Independence Scale developed for patients with cystic fibrosis (Patton, Graham, Varlotta, & Holsclaw, 2003), the Readiness to Change the Balance of Responsibility Scale (Kaugars, Kichler, & Alemzadeh, 2011) developed for patients with type 1 diabetes, and the Readiness Assessment (McPherson, Thaniel, & Minniti, 2009) developed for patients with sickle cell disease. The reviewers concluded that the support for the TR measures' psychometric properties was limited or, for some measures, psychometric properties were untested. They urged further validation studies on existing measures before their use could be broadly recommended for clinical use. They noted a generally applicable deficiency in testing the measures' content validity, internal consistency, and construct validity. Zhang and colleagues (2014) acknowledged that the lack of a "gold standard" measure of the TR construct was a barrier to establishing the criterion validity of newly developed TR measures, so

they encouraged measure developers to conduct longitudinal studies of TR measures' ability to predict subsequent transition and health outcomes.

**Independent review.** Independently, I conducted a systematic review to identify and evaluate the empirical support for existing TR measures. An additional aim of my review was to investigate the extent to which each of the TR measures covered facets of the TR construct described in While and colleagues' (2004) Sequential Transition and Developmental Transition Models, the two HCT models by Treadwell and colleagues (2011) and Schwartz and colleagues (2013) based on the application of Bronfenbrenner's biosocial-ecological systems model (Bronfenbrenner & Ceci, 1994), and the Health Care Transition Research Consortium's model of HCT (Betz et al., 2014). As mentioned earlier, these theoretical frameworks of HCT emphasized that the TR construct encompasses not only the AYA patient's acquisition of competencies (e.g., healthcare self-management, self-advocacy, health-related knowledge, interpersonal/communication skills) but also the successful changes in the roles of caretakers and healthcare providers as well as the patient's navigation of other, concurrent life transitions.

Between the dates of January 25, 2014 and May 23, 2014, I conducted searches in two electronic databases for relevant empirical and review papers: (a) PsycINFO (1987-present); and PubMed (1947-present). The search terms – “transition” AND “pediatric” AND “adult care” – yielded articles discussing a variety of specific pediatric-onset conditions as well as articles discussing transition issues as they generally pertained to AYAs. Search results were limited to peer-reviewed publications. I screened the titles and abstracts of 358 unique articles and identified 138 articles requiring full-text screening to determine whether the articles discussed or included a TR measure used with AYAs having one or more chronic, pediatric-onset medical conditions. I then reviewed these articles, as well as conference posters and transition program

websites referenced in these articles, and I found that thirty-four sources included information on the development and psychometric testing of twenty-two unique TR measures. Please see Figure 1 for a flow diagram with details about the article selection process.

Reviewed measures included seven generic measures and fifteen condition-specific measures designed for use with patients having complex bladder disorder, cystic fibrosis, diabetes, HIV, inflammatory bowel disease, kidney transplants, liver transplants, chronic rheumatic disorders, and sickle cell disease. The measure title, author information, description of the development process, structure and scoring information, required reading level (when available), and psychometric properties for each of the twenty-two TR measures are summarized in Table 1. Based on the EBA criteria, I classified one generic measure, the Transition Readiness Assessment Questionnaire (Sawicki et al., 2011), as an “approaching well-established” assessment, given the second publication by the measure’s creators that reported further testing and refining of the Transition Readiness Assessment Questionnaire (Wood et al., 2014). Three condition-specific measures – the Crohn’s and Colitis Knowledge Score (Eaden, Abrams, & Mayberry, 1999), the Developmentally Based Skills Checklist (Annunziato et al., 2011), and the How Much Do I Know About Sickle Cell Disease knowledge test (Baskin, Collins, Kaslow, & Hsu, 2002) – also met criteria for “approaching well-established,” as multiple publications by the measures’ creators indicated support for their reliability and validity. The Am I ON TRAC for Adult Care Questionnaire (Moynihan, 2012; Moynihan, Saewyc, Whitehouse, Paone, & McPherson, 2014) and the STARx Transition-Readiness Survey (Ferris et al., 2013) could not be assigned an EBA classification, as the development process and validation studies of the ON TRAC measure were reported only in an unpublished Master’s Thesis and conference posters; the STARx Transition-Readiness Survey’s factor structure was



described on the STARx transition program's website and no results of testing were reported in Ferris and colleagues' (2013) publication. The remaining sixteen TR measures were classified as "promising assessments."

The content areas covered by the reviewed TR measures are summarized in Table 2 (measures are arranged in the same order as they appear in Table 1). Relevant proposed mediators and moderators of successful HCT listed within the HCT Research Consortium model's Individual Domain were used to categorize the TR measures' content. Additional categories were derived based on commonalities among TR measures not mentioned in the HCT Research Consortium model. Over 50% of TR measures included items that assess patients' knowledge of their medical condition and/or their treatment regimen, patients' level of responsibility for healthcare tasks, and patients' ability to communicate with healthcare providers. Between 25% and 49% of TR measures included items that assess patients' ability to organize resources and services to meet health-related needs (e.g., making appointments, filling prescriptions, transportation to appointments, planning to take care of medical needs, obtaining interpreter services), to understand health insurance issues, to adhere to prescribed treatment regimens, to engage in general health-promoting behaviors, and to avoid high-risk behaviors. Fewer than 25% of measures included items that assess patients' ability to obtain and maintain a personal record of their medical information, knowledge of steps to take in a medical emergency (including knowing whom to call), clinic attendance, ability to advocate for needed services, understanding of basic anatomy and physiology, general independence (e.g., ability to manage money), perception and preferences regarding HCT, health literacy, and awareness of legal rights and protections. Content categorized as "Other" were assessed by only one or two TR measures (i.e., patient has identified a primary care provider, psychosocial issues, knowledge of types of

physicians to see as an adult and their contact information, post-high school plans and considerations, receiving financial help with school or work, engaging in diabetes-specific safety behaviors, knowledge of drug allergies, seeking reproductive counseling, ability to use a thermometer, having confidence with care, and social support and involvement).

Few of the reviewed measures reflected changes in parents'/caregivers' role and the recognition of the greater context of simultaneous transitions in multiple microsystems in which the HCT is embedded, which were aspects of TR emphasized in the While and colleagues' (2004) models and the two biosocial-ecological models (Schwartz et al., 2013; Treadwell et al., 2011). Only two of the TR measures included items or scales reflecting transition changes experienced by the parents/caregivers of the AYA patients – the Readiness for Transition Questionnaire (Gilleland et al., 2012) and the Transition Readiness Survey Adolescent/Young Adult and Parent Report versions (Fredericks et al., 2010). Single items on the Am I ON TRAC for Adult Care Questionnaire (Moynihan, 2012) and the Transition Knowledge Questionnaire (Newland, 2008) assessed the AYA's non-HCT transition processes.

The variety of methods by which the content for the reviewed TR measures were determined (e.g., atheoretical vs. theory-based approaches; literature reviews; use of existing measures as models; focus groups with patients, family members, and healthcare providers; consultations with experts) and the different needs of patients with different chronic conditions contributed to the diversity of the measures' content. However, the commonalities among measures confirmed the perception that condition and treatment knowledge, the assumption of responsibility for healthcare tasks, communication skills, ability to organize resources and healthcare services, and insurance knowledge are important to successful transition to adult care and functioning within that system.

My review of a broader range of available TR measures led to several conclusions: (a) there is a need to describe the theoretical models influencing TR measure development, as only four of the twenty-two reviewed measures reported having a theoretical basis; (b) there is a need to test and report the reading levels required to comprehend and respond to the TR measures, as reading levels were reported for only six of the twenty-two measures and ranged from the fourth-grade to the tenth-grade reading level; (c) there is a need for consistent health literacy screening, as this is an often assumed but unconfirmed TR skill; (d) there is a need to test and report test-retest reliability of TR measures over short time periods, as test-retest reliability was reported for only three of the twenty-two measures and determining this property is a prerequisite to the use of TR measures to assess patient progress towards TR goals; (e) there is a need to compare TR measures that assess patients' or parents' *perceptions* of transition-related skills or knowledge with demonstrations of *actual* competency, or to include direct measures of *actual* competency in a TR measure; (f) there is a need to test TR measures' predictive validity, particularly how well TR measures predict HCT success, as this is the premise underlying the definition of TR, which has not been tested yet; (g) there is a need to test and report the incremental validity of a TR measure by comparing its relationship with transition outcomes to the relationship between transition outcomes and patient age; and (h) there is a need to test and report the sensitivity of a TR measure to the effects of transition preparation interventions, particularly of interventions that incorporate baseline results from TR assessment into their implementation.

### **Study Purpose and Hypotheses**

Given the need to test and refine models of HCT empirically, this study was conducted to evaluate the ability of specific socio-demographic, medical, and TR factors to predict transition outcomes. I first evaluated the psychometric properties of the Transitioning Preparedness

Survey (TPS), a TR measure developed for repeated use with patients of multiple chronic condition groups as well as survivors of childhood cancer. The TPS was developed by the Transition Program of Children's Mercy Hospital (CMH), an academic pediatric medical center. The CMH Transition Program had expressed interest in further developing and establishing the psychometric properties of the TPS to support expansion of its use for research purposes as well as to justify its use as a clinical tool. I then analyzed the relationships between potential transition outcome predictors and transition outcomes through a retrospective study involving data collection during a pre-transfer period and a post-transfer period. Specific study hypotheses included:

**Hypothesis 1: Reliability of the TPS.** I hypothesized that the different versions of the TPS would each demonstrate adequate overall internal consistency (i.e.,  $\alpha \geq 0.70$ ) and that their subscales ("Knowledge," "Skill," and "Taking Charge") would each demonstrate adequate internal consistency.

**Hypothesis 2: Validity of the TPS.** I hypothesized that the TPS versions would each demonstrate concurrent, convergent, and predictive validity. Moderate, positive correlations among the TPS subscales would support concurrent validity. Moderate, positive correlations between the TPS and related constructs (i.e., patient age; number and percentage of outpatient, pediatric specialty clinic appointments attended; percentage of all outpatient pediatric appointments attended; and number of appointments during which transition preparation was discussed) would support convergent validity. Higher TPS scores for patients at lower risk for neurocognitive difficulties compared to those for patients at higher risk would also support convergent validity. Finally, positive relationships between TPS scores and subsequent

transition outcomes (i.e., success of transition to adult primary care, success of transition to adult specialty care) would support predictive validity.

Additionally, I hypothesized that the TPS would demonstrate incremental validity by improving the prediction of transition outcomes of regression models in which the TPS was included as a predictor in addition to patient age at last pediatric transition (pre-transfer) appointment.

**Hypothesis 3: Identifying general (i.e., not condition-specific) predictors of successful transition.** I aimed to explore the relationships between individual potential predictors and transition outcomes (i.e., successful, partially successful, or unsuccessful transition to adult primary medical care and, if applicable, to adult specialty care), as well as the relationships between categories of predictors and transition outcomes. Based on previous studies of transition outcomes, I expected the categories of socio-demographic factors, medical characteristics comparable across condition groups, and indicators of engagement in pediatric and transition preparation services, as well as the TPS results, to contribute significantly to an ordinal logistic regression model predicting transition success.

In summary, the aims of the study were to test the psychometric properties of the TPS and to identify predictors of transition outcomes. The TPS's psychometric properties were evaluated to determine whether it was a reliable and valid indicator of TR. Testing the TPS's ability to predict subsequent transition success would fill an important gap in the TR measure development literature, as this type of predictive validity has not been tested in the currently available TR measures. Testing the incremental value of the TPS as a predictor of transition outcomes over patient age would provide empirical support for or against the use of a TR measure in making decisions regarding the timing of transfer. Statistically modeling the

prediction of transition success based on socio-demographic, medical, pediatric and transition service engagement, and TR factors would facilitate identification of factors that may support transition success or may indicate elevated risk for unsuccessful transition. Identifying these supportive and risk factors and quantifying their relationships with transition outcomes would contribute to the nascent empirical basis for developing more comprehensive models for understanding HCT.

## **Method**

### **Participants**

Data for the current study were collected from both a review of the medical records of patients currently or previously treated at CMH and also follow-up phone calls made to the patients who transitioned out from CMH. All patients who met the following criteria were eligible for inclusion in the medical record review: (a) the patient previously received or is currently receiving medical services through CMH's Survive and Thrive Clinic (pediatric cancer survivors), either of two rehabilitation medicine clinics (Spinal Defects Clinic, Muscle Nerve Clinic), the Endocrine Disorders in Cancer Survivors (EDICS) Clinic, or the Rheumatology Transition Clinic; (b) the patient was diagnosed with one or more chronic medical condition(s) before the age of twenty-one years, and/or the patient had been diagnosed with cancer before the age of twenty-one years and had achieved cancer remission before the time of their last appointment at CMH; and (c) the patient completed the Transitioning Preparedness Survey at least once as part of transition preparation services at CMH. Medical records for patients seen at CMH before January 1, 2015 were reviewed with an emphasis on patients who were more likely to have transitioned to adult care by the time of this study's data collection phase.

A subset of the patients included in the medical record review was contacted by phone for the follow-up collection of transition outcome data. This subset of patients was identified by the following criteria: (a) the patient was eighteen years or older at the time of the follow-up call; and (b) the patient had not received medical services from CMH (except emergency room services) for over one year since the last attended appointment at CMH and had no future appointments scheduled at CMH, or the patient's medical record documented referral to an adult primary care provider and the termination of regular healthcare services at CMH. If a patient in this follow-up subgroup provided written authorization for the research team to contact his or her adult primary care provider and/or specialty care provider, I attempted to contact the adult-care provider(s) as part of the study's follow-up data collection phase.

## **Measures**

**Medical chart review.** Patient socio-demographic information, medical characteristics, pediatric and transition preparation services engagement, and TR variables were abstracted from the medical record. Please see Appendix A for the medical chart review Data Abstraction Protocol. Specific socio-demographic information included: patient gender, age (at the time of the most recent CMH appointment), race/ethnicity, preferred language, educational level, employment status, county and state of residence, insurance type/status, qualification for CMH financial aid, and legal guardianship status (for patients 18 years and older). Specific medical characteristics included: CMH transition clinic through which the patient primarily received care, primary chronic medical condition diagnosis (or primary cancer diagnosis), secondary chronic medical conditions (and neurocognitive and neurodevelopmental disorders or disabilities), psychiatric conditions, age at time of diagnosis of primary chronic medical condition, characteristics unique to cancer survivors (e.g., cancer treatment components, age when active

treatment ended, experience of cancer recurrence or secondary cancer), indicators of condition complexity, and components of medical treatment regimen (at the time of the most recent CMH appointment). The number and percentage of appointments attended that were scheduled in the primary CMH transition clinic, as well as the percentage of all CMH appointments attended, were recorded as indicators of engagement in pediatric healthcare. Transition preparation variables included the number of appointments during which HCT issues were discussed (e.g., patient education about HCT was provided, Transitioning Preparedness Survey responses were discussed, a referral to an adult healthcare provider was given), the number of times and the dates on which the patient completed CMH's Transitioning Preparedness Survey (TPS), and the TPS item responses. The inclusion of variables in the Data Abstraction Protocol was influenced by variables listed in the Health Care Research Consortium's HCT model's Individual Domain (that were routinely recorded in the medical record) and the transition-related questions used in several national surveys (McManus et al., 2013; Richmond et al., 2012).

**Medication Regimen Complexity Index (MRCI; George, Phun, Bailey, Kong, & Stewart, 2004)** (Appendix B). From the medical chart reviews, I calculated the MRCI, a score summarizing regimen complexity that takes into account the dosage form (e.g., tablets, eye drops, injections), dosing frequency, and additional directions included in prescriptions for each medication. Higher scores indicated greater regimen complexity. George et al. (2004) demonstrated the MRCI's criterion validity by correlating its ranking of theoretical medication regimens with an expert panel's rankings. They also demonstrated high interrater and test-retest reliabilities for the total score and individual sections' scores of the MRCI.

**Transitioning Preparedness Survey (TPS; Children's Mercy Hospital)** (Appendix C, Appendix D, and Appendix E). The three versions of the TPS (for patients age 12-14, 15-17,



and 18 and older years) were constructed to assess transition-related abilities and attitudes that patients in the specified age groups were expected to develop. The TPS forms also prompted patients to develop several specific transition goals to accomplish before the next appointment and to record any comments or questions. The Knowledge subscale included items assessing patients' perceived ability to discuss their medical history, specific condition, treatment components, healthcare team, and effects of the condition on personal development and behaviors. The Skill subscale included items assessing patients' perceived ability to keep track of health-related information, participate in medical appointments, recognize and report when help is needed for managing health problems, and manage medications. The Taking Charge subscale included items assessing patients' attitudes toward self-management of health, social support, and transition into adult healthcare. For each item, there were three response choices – “Yes! I can do this” (1 point), “I want to learn how to do this” (0.5 point), and “Someone else will have to do this. Who?” (0 point). The TPS 12-14 Version and the TPS 15-17 Version provided two response choices – “Yes” (1 point) and “No” (0 point) – for the Taking Charge subscale items. Responses to the TPS may be summarized by the sum of individual items' scores or by the percentage of items endorsed by the patient at the “Yes! I can do this” level. The readability levels of the TPS versions corresponded to the following Flesch-Kincaid Grade Levels: 4.0 for the TPS 12-14 Version and 8.8 for the TPS 15-17 Version and the TPS 18+ Version. Within the CMH Survive and Thrive, Spinal Defects, Muscle Nerve, EDICS, and Rheumatology Transition clinics, the TPS was administered repeatedly so that clinicians could identify specific targets for transition education and intervention and could track individual patients' development of TR skills.

The TPS was developed over the course of several years by members of CMH's Transition Program, an interdisciplinary team of leaders representing multiple divisions within the hospital. The team members included Ann Modrcin, M.D.; Sara Gardner, M.D.; David Westbrook; Paige Mundy-Young; Mary Ann Jackson, M.D.; Terri Hickam, M.S.W., L.C.S.W., L.S.C.S.W., C.C.M.; Edie Roderick, R.N., M.S.N.; Talia Collier, M.D.; Mary Brock; Jim Grimm, M.A., M.T.; Serkan Toy, Ph.D.; and Diane Kennedy, R.N., Ph.D. The content of TPS items was based on the Good 2 Go Transition Program's Transition Readiness Checklist for Patients (Hospital for Sick Children, Toronto, Canada; <https://www.sickkids.ca/Good2Go/What-we-do/Readiness-checklists/index.html>). The Good 2 Go checklist was a 26-item measure that was adapted from *Setting the Trac – A Resource for Health Care Providers* (Paone, 2000) and revised based on the Self-Management Skills Assessment Guide (Williams et al., 2010). The psychometric properties of the Good 2 Go checklist have not been evaluated.

The original TPS's three versions were used with patients 12-14 years of age (Flesch-Kincaid Grade Level, 8.7), patients 15-17 years of age (Flesch-Kincaid, 9.4), and patients 18+ years of age (Flesch-Kincaid, 10.3). The twenty-one items in each of the three versions addressed the same skills but represented increasingly sophisticated or independent ways of employing these skills in accordance with the creators' expectations of patients' skill level and educational needs for each age range. For each item, there were six response choices – “I never do this (someone does this for me),” “I rarely do this (but I'm starting to try),” “I do this sometimes and sometimes don't,” “I do this often,” “I always do this (I'm there!),” or “Does not apply to me.” The TPS was initially used as a skills checklist to help clinicians and patients identify specific transition goals and prompt follow-up on these goals at subsequent visits.

Dr. Modrcin and colleagues sought feedback on the TPS's content and clarity from the Family Advisory Board, other clinicians involved in transition services, the director of Patient Advocacy, and the coordinators of Family Centered Care. They also sought feedback on the utility of the TPS from patients and their families. The feedback received and the Transition team's goals of shortening the TPS, reducing the required reading level, and maximizing the TPS's utility across multiple medical populations guided the modification of the TPS. Modifications resulted in the elimination of some items resulting in the current number of items in each version – fifteen items in the TPS 12-14 Version (five Knowledge items, six Skill items, and four Taking Charge items), eighteen items in the TPS 15-17 Version (six Knowledge, eight Skill, and four Taking Charge items), and seventeen items in the TPS 18+ Version (seven Knowledge, six Skill, and four Taking Charge items). The response options were also changed from six choices to two-to-three choices.

**Follow-up phone surveys.** Information about transition outcomes was gathered through follow-up phone calls to young adults who were formerly treated at CMH through the previously specified clinics. When a young adult had a legal guardian, the guardian was invited to serve as the proxy informant. Phone calls were conducted in accordance with an interview script.

For each young adult who agreed to share his or her transition outcome information with this study, the following information was obtained through the phone survey: (a) the dates of each outpatient appointment the young adult scheduled with any adult primary care provider seen after the last CMH appointment; (b) which primary care outpatient appointments the young adult attended, if appointments were scheduled; (c) the dates of each outpatient appointment the young adult scheduled with referred adult-care medical specialists, if the young adult's CMH medical chart indicated a referral to one or more specialists (the young adult was also asked for

dates of appointments scheduled with any other adult-care medical specialists); (d) which outpatient specialist appointments the young adult attended, if appointments were scheduled; (e) satisfaction with the transition process (Likert scale: 0 = *entirely dissatisfied*, 1 = *moderately dissatisfied*, 2 = *mildly dissatisfied*, 3 = *mildly satisfied*, 4 = *moderately satisfied*, 5 = *entirely satisfied*); and (f) suggestions for improving the transition process. Please see Appendix F for the Data Collection Form for these follow-up phone calls to the young adults.

The following outcome variables were calculated based on the quantitative information provided from the phone surveys:

***Primary outcome.*** The primary outcome variable was the success of transition to an adult primary care provider reported by the young adult (T-PCP<sub>YA</sub>). As all patients transitioning out of pediatric care were expected to establish care with an adult primary care provider, this outcome variable could be measured for everyone who had concluded their care at CMH. T-PCP<sub>YA</sub> was a categorical variable with three categories: *successful transition*, *partially successful transition*, and *unsuccessful transition*.

Criteria for a T-PCP<sub>YA</sub> *successful transition* were that the young adult attended at least one appointment with any adult primary care provider within the first year after the last CMH transition clinic appointment *and* had attended, on average, one or more primary care appointments per year since the young adult's last CMH appointment. If the time between the young adult's last CMH appointment and the follow-up call was less than one year, then the criteria for a T-PCP<sub>YA</sub> *successful transition* were met if the patient had attended *or* scheduled at least one appointment with any adult primary care provider to occur within the first year since the last CMH appointment. This operationalization of the "successful transition" construct aimed to reflect the ideal of uninterrupted and continuous care.

The criteria for a T-PCP<sub>YA</sub> *partially successful transition* were that the young adult had attended at least one appointment with any adult primary care provider since the young adult's last CMH appointment *and* either had no primary care appointments during the first year since the young adult's last CMH appointment or had attended, on average, less than one appointment per full year since the last CMH appointment.

A T-PCP<sub>YA</sub> *unsuccessful transition* was defined by the young adult's attending no appointments with any adult primary care provider since the young adult's last CMH appointment, if the time since the last CMH appointment was at least one year. If the time since the last CMH appointment was less than one year, the criterion for a T-PCP<sub>YA</sub> *unsuccessful transition* was that the patient had not scheduled an appointment with any adult primary care provider to take place within the year following the young adult's last CMH appointment.

***Secondary outcome.*** The secondary outcome variable was the success of transition to adult-care specialists reported by the young adult (T-SPEC<sub>YA</sub>). Not all transitioning patients required services from adult specialty providers; thus, analyses involving transition outcomes to adult-care specialists included the subset of patients who received such recommendations from a CMH physician. T-SPEC<sub>YA</sub> was a categorical variable with three categories: *successful transition*, *partially successful transition*, and *unsuccessful transition*.

The criterion for a T-SPEC<sub>YA</sub> *successful transition* was that the young adult had attended one or more appointments with each type of recommended adult-care specialist (regardless of whether a specific physician was the one referred by CMH) within the first year following the last CMH transition clinic appointment. If the time between the young adult's last CMH appointment and the follow-up call was less than one year, then the criterion for a T-SPEC<sub>YA</sub>

*successful transition* was met if the patient had attended *or* scheduled at least one appointment with each type of specialist to occur within the first year following the last CMH appointment.

The criterion for a T-SPEC<sub>YA</sub> *partially successful transition* was that the young adult had attended one or more appointments with at least one adult-care specialist (but not all the recommended specialists) since the young adult's last CMH transition clinic appointment. If the time between the young adult's last CMH appointment and the follow-up call was less than one year, then the criterion for a T-SPEC<sub>YA</sub> *partially successful transition* was met if the patient had attended *or* scheduled one or more appointments with at least one adult-care specialist (but not all the recommended specialists) to occur within the first year following the last CMH appointment.

A T-SPEC<sub>YA</sub> *unsuccessful transition* was defined by the young adult's attending no appointments with any adult-care specialists since the young adult's last CMH transition clinic appointment. If the time since the last CMH appointment was less than one year, the criterion for a T-SPEC<sub>YA</sub> *unsuccessful transition* was that the patient had not scheduled an appointment with any adult-care specialists to take place within the year following the young adult's last CMH appointment.

Primary and secondary outcome variables based on adult healthcare providers' records had been proposed to provide more objective measures of these outcomes. However, due to the limited response rate of adult healthcare providers to requests for study-related information, these variables could not be included in analyses.

### **Study Procedure**

The study team obtained approval from the Children's Mercy Hospital Institutional Review Board (IRB), and the University of Kansas – Lawrence campus IRB agreed to rely on

the review of the CMH IRB. Informed consent was not required for the process of collecting de-identified data through a retrospective review of patients' medical charts. Oral and written consent were obtained from the young adults who participated in the follow-up phone surveys. Written authorizations for the release of information were obtained from young adults who provided consent for the research team to contact their adult-care providers.

Clinicians involved in each of the participating clinics identified patients meeting inclusion criteria for the study's medical record review portion. These clinicians were Wendy (McClellan) Hein, R.N., M.S.N., C.P.N.P. and Kyla Alsman, R.N. in the Survive and Thrive clinic; Diane Kennedy, R.N., Ph.D. in the two rehabilitation medicine clinics (Spinal Defects Clinic and Muscle Nerve Clinic); Julia Broussard, M.D. and Katherine Williams, R.N. in the Endocrine Disorders in Cancer Survivors (EDICS) clinic; and Rawni Anderson, M.A., CCRC in the Rheumatology Transition Clinic.

I reviewed the medical charts of these patients up to appointments scheduled before January 1, 2015, and I abstracted relevant information in accordance with the Data Abstraction Protocol (Appendix A). To assess interrater reliability with respect to the process of data abstraction, a second data abstractor (Ali Calkins, M.A.) completed an independent review of 10% of participants' medical records and the following statistical analyses were conducted. Cohen's kappa (Cohen, 1960) and intraclass correlations were calculated to examine interrater reliability for coding of categorical and continuous variables, respectively, that required rater judgment when translating medical record information into coded data for the research database. Cohen's kappa values ranged from 0.37 – 1.00 ( $p \leq 0.04$ ) across categorical variables and intraclass correlation values ranged from 0.87 – 1.00 ( $p < 0.001$ ), indicating acceptable interrater reliability. I resolved disagreements between the data abstractors through re-examination of the

medical record. I also re-examined the medical record to check codes for variables that were coded least reliably. I then conducted relevant calculations based on the chart review data as described in the Data Abstraction Protocol, calculated summary scores for the TPS, and calculated the Medication Regimen Complexity Index values for each patient.

Through the medical record review and consultation with the CMH clinicians, I identified patients who meet criteria for inclusion in the follow-up phone survey portion of the study. I mailed out letters to these eligible patients that provided a brief description of the study and notification of future phone calls related to this study. The letter was signed by Dr. Joy Fulbright (Survive and Thrive oncologist) and Dr. Ann Modrcin (rehabilitation medicine physician), who served as the principal investigator and co-investigator, respectively, on this study. Copies of the study's consent form and authorization to release information from healthcare providers to the research team were included with the letter. To establish contact with a potential participant, I made a maximum of three phone calls, unless the patient responded indicating interest. If I left a voicemail message on a potential participant's personal cell phone, I also sent a text message prompting the patient to listen to the voicemail message and to call back if interested in additional information about study participation. When speaking directly with a potential participant, I followed a phone interview script to describe the study and ask about the person's interest in study participation. When an individual indicated interest, I reviewed the study's consent form and requested that the individual provide both oral and written consent for use of the survey information in the research study and for permission to contact adult healthcare providers. I conducted the phone consent process through a three-way conference call so that Ali Calkins could witness the consent provided by the participant. Each participant signed a copy of the consent form and mailed the form to the research team in a pre-stamped and addressed



envelope provided with the study letter. For each phone consent, Ali and I each signed a copy of the consent form. I then administered the questions on the Data Collection Form for Follow-up Calls to Adult Participants (Appendix F).

When patients provide authorization for the research team to contact their adult healthcare providers, I called the providers' offices and attempted to establish contact with the providers, nurses, or office administrators. I faxed a copy of the authorization for the release of information to the office. I then attempted to obtain information related to appointments that the young adult had scheduled and attended at the adult healthcare provider's clinic, transfer of records from CMH to the adult healthcare provider's clinic, and the provider's satisfaction with and feedback on the transition process. Adult healthcare providers were offered the options of completing the survey by phone or online (i.e., REDCap survey). As only one adult-care provider completed the follow-up survey, adult-care provider data were not included in statistical analyses.

### **Statistical Analyses**

I conducted data analyses using the IBM SPSS Statistics version 23 program and R version 3.2.1 (R Core Team, 2015) along with the psych package for R (Revelle, 2016). The significance level for analyses was set at 0.05. For directional hypotheses, I conducted one-tailed tests and otherwise conducted two-tailed tests. After conducting preliminary, descriptive analyses of individual variables, I conducted bivariate and multivariate analyses to test the study's hypotheses.

**Missing data.** If a case was missing more than 50% of data in any category (socio-demographic data, medical variables, pediatric and transition services engagement, TPS, transition outcomes), it was excluded from analyses. Two cases missing more than 50% of TPS

item responses were excluded for this reason. The dataset composed of information abstracted from the medical records of 152 cases was missing 0.31% of all values. Missing data were found on 14% of the medical record-related variables. At most, an individual variable was missing less than 8% of values. Due to the focus of this study, missing values for TPS items were of primary concern. All items from the TPS that was last administered during a patient's CMH transition clinic appointment were missing 1.3%-7.9% of their values. I used SPSS procedures to determine the mechanism of missingness for the TPS items. Little's Missing Completely At Random test was significant ( $\chi^2(550) = 691.042, p < 0.001$ ), indicating that the mechanism of missingness was not Missing Completely At Random. It was assumed that the data were Missing At Random – that is, that missingness was not related to the underlying values of the missing data but to other observed variables included in the analysis. Correlations conducted as part of the missing values analysis indicated that the missingness on TPS items were interrelated, supporting the assumed Missing At Random mechanism.

SPSS multiple imputation was used to estimate missing values in accordance with Tabachnick and Fidell's (1996) recommendations. Multiple imputation was selected for the purpose of obtaining more reliable parameter estimates from statistical analyses conducted on these imputed datasets compared with parameter estimates following traditional methods of addressing missing data (e.g., deletion and single imputation) (Baraldi & Enders, 2010). Twenty imputations were conducted per the rule of thumb given by Graham and colleagues (2007). Reported results of statistical analyses involving the TPS were pooled parameter estimates derived from SPSS multiple imputation procedures. However, descriptive statistics summarizing sample demographics and medical characteristics were calculated on the original dataset.

## Results

### Medical Record Review Study Sample

The CONSORT diagram (Figure 2) summarized selection of cases for inclusion in the medical record review portion of the study and recruitment of participants for the follow-up phone survey portion of the study. The reader is referred to the CONSORT diagram for details regarding the number of cases included in the study from each of the individual transition clinics, as the following will discuss the overall number of cases included in the study from all of the participating clinics. Clinicians within the CMH transition clinics referred a total of 310 patients for the study's medical record review, as these patients had each completed at least one TPS before January 1, 2015. Patients who were likely to have transitioned before or within the year 2015 (i.e., patients who were eighteen-years-old or older by January 1, 2015) were targeted for the medical record review. The 156 patients (50.3%) who were younger than eighteen-years-old at January 1, 2015 were not included in the medical record review at this stage of the research study, but their medical records will be reviewed during a later stage of the study and their data will be included in a manuscript to be submitted for publication. An additional two patients were excluded from the medical record review due to missing data on more than 50% of TPS items. For the current stage of this study, the medical records for 152 patients (49.7% of referred patients) were reviewed, and abstracted data were included in analyses testing the psychometric properties of the TPS. Of these 152 patients, 110 had completed the TPS 18+ Version and 42 had completed the TPS 15-17 Version when they were last administered the TPS prior to January 1, 2015.

Patients seen in the Survive and Thrive Clinic comprised 43.4% ( $n = 66$ ) of the 152 patients included in the medical record review. Patients seen in the Muscle Nerve and Spinal

Defects clinics comprised 4.6% ( $n = 7$ ) and 28.9% ( $n = 44$ ) of this sample, respectively. Patients seen in the EDICS Clinic comprised 3.9% ( $n = 6$ ) of this sample. Patients seen in the Rheumatology Transition Clinic comprised 1.9% ( $n = 3$ ) of this sample. Patients seen in both the Survive and Thrive and EDICS clinics comprised 17.1% ( $n = 26$ ) of this sample.

Characteristics of the study sample as a whole are described below. The reader is referred to Table 3, Table 4, Table 5, and Table 6 for more detailed information regarding the characteristics of each CMH transition clinic subsample. Due to the limited number of patients from the Muscle Nerve, EDICS, and Rheumatology Transition Clinics who were eligible for this study, no analyses were conducted to measure between-clinic differences in socio-demographic, medical, and pediatric and transition service engagement characteristics. The number of patients varied widely across the participating clinics, as the transition clinics differed in their lengths of operation (e.g., the Rheumatology Transition Clinic was one of the newer transition clinics) and in the frequencies with which the conditions treated within those clinics occurred.

Slightly over a half of study patients were female (57.2%). The most common racial/ethnic background was non-Hispanic White (77.6%), and English was the preferred language for almost all patients (96.1%). At the time of these patients' last transition clinic appointments before January 1, 2015, they ranged in age from 17.1 years to 25.3 years ( $M(SD) = 19.6 (1.68)$  years). Many of these patients were attending a post-secondary education program (41.4%), and about half of these patients were attending high school (25.0%) or had graduated from high school or passed the GED tests (24.3%). Some of these patients were employed full-time (19.1%) or part-time (11.8%). The majority of patients (69.7%) had private health insurance, 23.0% had public health insurance, and 7.2% were paying for medical services without health insurance at the time of their last transition clinic appointment before January 1,

2015. A small number of patients (7.9%) were receiving financial assistance from CMH. Patients traveled 1.8 miles to 224 miles ( $M(SD) = 48.8 (50.4)$  miles) from their area of residence to CMH to receive care. Of the 129 patients who were eighteen years or older at their last transition clinic appointment before January 1, 2015, 7.0% had a legal guardian or had a caregiver pursuing legal guardianship. Please see Table 3 for a detailed summary of socio-demographic characteristics of patients from each of the participating transition clinics.

Patients in the study sample were seen in the transition clinics for a variety of chronic medical conditions (e.g., myelomeningocele, Charcot-Marie-Tooth disease, juvenile idiopathic arthritis, etc.) or history of pediatric cancer (e.g., leukemia, lymphoma, medulloblastoma, rhabdomyosarcoma, etc.). Patients were diagnosed with these chronic conditions or cancer between the ages of 0 years – 19.6 years of age ( $M(SD) = 6.3 (6.1)$  years). In addition to their primary chronic medical conditions or previous diagnosis of cancer, these patients had 0-13 ( $M(SD) = 3.2 (2.6)$ ) additional chronic medical conditions and/or cancer-related late effects. About one third of study patients (35.5%) had been diagnosed with one or more neurocognitive or neurodevelopmental disorder (e.g., neurocognitive disorder secondary to a general medical condition, intellectual disability, Attention-Deficit/Hyperactivity Disorder, Autism Spectrum Disorder). About one fifth of patients (22.4%) had been diagnosed with one or more psychiatric disorders (e.g., depression, anxiety, etc.). The majority (71.8%) of patients had a history of one or more major surgical procedures. Patients had received care from 1-15 ( $M(SD) = 4.9 (3.2)$ ) different pediatric specialty clinics within CMH to manage their primary and secondary chronic medical conditions. At the time of their last transition clinic appointment before January 1, 2015, the majority of patients' medical regimens included medications and/or supplements (82.9%). Records indicated that patients had a median of 2.5 medications and supplements

(ranging from 0 to 25 medications and/or supplements). Medical regimens also included physical exercises (e.g., physical therapy, occupational therapy, physical exercise recommendations for weight management) for 40.1% of patients, dietary recommendations for 44.7% of patients, self-monitoring recommendations (e.g., blood glucose monitoring) for 0.7% of patients, and other regimen components (e.g., self-catheterization) for 31.6% of patients. Please see Table 4 for a detailed summary of medical characteristics by individual transition clinics.

In terms of the study sample's pediatric and transition services engagement, patients had participated in 1-8 ( $M(SD) = 3.0 (1.5)$ ) pre-transfer appointments during which healthcare transition issues were directly discussed with the patient and/or their caregivers. Attendance rates for appointments in the transition clinics were skewed towards perfect attendance rates ( $M(SD) = 95.7\% (11.5\%)$ ; median = 100.0%; rates ranged from 33.3%-100.0%). Overall attendance rates for outpatient appointments at CMH ranged from 47.1%-100.0% ( $M(SD) = 83.3\% (11.1\%)$ ). Please see Table 5 for a detailed summary of service engagement characteristics by individual transition clinics.

The 110 patients administered the TPS 18+ Version endorsed, on average, 77.5% of TPS items at the "Yes! I can do this" level. On average, patients endorsed 76.8% of the Knowledge subscale items, 73.8% of the Skill subscale items, and 85.1% of the Taking Charge subscale items. The 42 patients administered the TPS 15-17 Version endorsed, on average, 68.0% of TPS items at the "Yes! I can do this" level. On average, these patients endorsed 71.0% of the Knowledge subscale items, 61.3% of the Skill subscale items, and 76.8% of the Taking Charge subscale items. Please see Table 6 for a detailed summary of TPS scores by individual transition clinics.

### **Follow-up Phone Survey Subsample**

The 152 patients included in the medical record review were screened for eligibility for the follow-up phone survey portion of the study. Of these patients, 88 were ineligible for participation in the phone survey. Specifically, 87 patients had not transitioned out of pediatric care (i.e., they continued to receive care from CMH following January 1, 2015) and one patient died before the current study was conducted. I attempted to contact the 64 young adults (42.1% of patients included in the medical record review) who were eligible for the phone survey. Of these 64 young adults, 55 (85.9%) did not consent to completing the phone survey; specifically, six declined the invitation to participate, six indicated interest in the study but did not complete the consent procedure even with follow-up phone calls, three did not have a working phone number within CMH's records, and forty made no response to my attempts to contact them through voice and text messages. Of the 64 eligible young adults, nine (14.1%) completed the research consent procedure and responded to the phone survey. Because of the small number of survey completers, quantitative analyses testing hypotheses involving the transition outcome measures (e.g., predictive and incremental validity of the TPS, exploration of transition outcome predictors) could not be conducted. Qualitative data obtained through the phone surveys with these nine young adults will be summarized.

The 55 young adults who were eligible and approached for the follow-up phone survey but did not complete the consent procedure were compared with the nine young adults who completed the phone survey. Results of a MANOVA indicated that the survey completers and non-completers differed significantly when their demographic, medical, and pediatric and transition services engagement characteristics were compared ( $F(17,46) = 1.956, p = 0.036$ , Wilks'  $\Lambda = 0.580$ , partial  $\eta^2 = 0.420$ ). More specifically, the survey completers were, on

average, 1.4 years older than the non-completers at the time of their last pediatric transition clinic appointment ( $F(1) = 4.209, p = 0.044, \text{partial } \eta^2 = 0.064$ ). Additionally, the survey completers' TPS Skill subtest scores were, on average, 21.9% higher than non-completers' scores ( $F(1) = 6.022, p = 0.017, \text{partial } \eta^2 = 0.089$ ). Separate analyses of categorical demographic, medical, and pediatric and transition services engagement characteristics indicated that survey completers and non-completers differed in their employment status at the time of their last pediatric transition clinic appointment ( $\chi^2(2) = 9.829, p = 0.007$ ), as survey completers were more likely to have had part-time employment (44.4% of completers compared to 9.1% of non-completers) and survey non-completers were more likely to have had full-time employment (32.7% of non-completers, and 0% of completers) at that time. As these findings indicated some significant differences between survey completers and non-completers, the transition outcomes reported by the survey completers likely were not representative of the larger population of individuals who have transitioned out of pediatric care. However, the transition outcome data gathered through this study's survey may be useful in informing continuing research in this area.

Table 7 summarized the socio-demographic characteristics, medical characteristics, and rates of engagement in pediatric and transition services of the nine survey completers. In terms of socio-demographic characteristics, eight of the nine survey completers were female (88.9%), seven were White (77.8%), and eight spoke English as their preferred language (88.9%) while one spoke English as a second language without need for an interpreter. All of the survey completers were cancer survivors who had been seen in the Survive and Thrive transition clinic at CMH. Two of the survey completers had also been seen in the EDICS Clinic as well (22.2%). These individuals ranged in age from 19.5 years to 23.4 years ( $M(SD) = 21.7 (1.2)$  years) at the time of their last CMH transition clinic appointment. At that time, two thirds of these individuals



were attending post-secondary educational programs, while the other third had graduated from a post-secondary program. Four of the nine survey completers were employed part-time (44.4%). The majority of these individuals had private health insurance when they were receiving care at CMH (88.9%), while one individual was paying for medical services without health insurance. The distance between survey completers' areas of residence (at the time they were receiving care at CMH) and CMH ranged from 9.7 miles to 155.0 miles ( $M(SD) = 56.8 (55.0)$  miles). None of the survey completers had legal guardians, and thus, they each responded directly to the phone survey.

In terms of their medical characteristics, the survey completers ranged in age at the time of cancer diagnosis from 0.5 years to 17.1 years ( $M(SD) = 8.0 (5.1)$  years) and had 0-9 ( $M(SD) = 3.8 (3.2)$ ) secondary chronic medical conditions and/or cancer-related late effects. Less than half of the survey completers had been diagnosed with one or more neurocognitive or neurodevelopmental disorders (44.4%), and less than a quarter of the survey completers had been diagnosed with one psychiatric disorder (22.2%). All but one survey completer had undergone a major surgical procedure as a pediatric patient (88.9%). The survey completers had received care from 1-6 ( $M(SD) = 3.1 (1.7)$ ) different medical specialty clinics at CMH. At the time of their last transition clinic appointments, the survey completers had been prescribed 0-6 ( $M(SD) = 2.9 (2.0)$ ) outpatient medications and/or supplements. They had attended 1-5 pediatric appointments during which healthcare transition issues were directly discussed. Attendance rates for the transition clinics were high (median = 100.0%), and overall attendance rates for outpatient appointments at CMH ranged from 58.3%-95.4% ( $M(SD) = 78.8% (14.0%)$ ). TPS 18+ Version scores for the group of survey completers indicated that these individuals endorsed, on average, 89.5% of TPS items at the "Yes! I can do this" level. On average, survey completers

endorsed 84.1% of the Knowledge subscale items, 98.1% of the Skill subscale items, and 86.1% of the Taking Charge subscale items.

### **Testing Hypothesis 1: Reliability of the Transitioning Preparedness Survey (TPS)**

Following the recommendations of Gadermann, Guhn, and Zumbo (2012), the internal consistencies of the TPS 18+ Version and the TPS 15-17 Version were assessed through calculating ordinal  $\alpha$  values using R version 3.2.1 and the psych package. The internal consistencies of both versions' overall scales and three subscales were adequate. For the TPS 18+ Version ( $n = 110$ ), ordinal  $\alpha$  values were as follows: overall scale (ordinal  $\alpha = 0.93$ ), Knowledge subscale (ordinal  $\alpha = 0.89$ ), Skill subscale (ordinal  $\alpha = 0.87$ ), and Taking Charge subscale (ordinal  $\alpha = 0.84$ ). Examination of changes in ordinal  $\alpha$  values when individual items were removed from the TPS 18+ Version indicated that internal consistencies of the overall scale and the subscales would not be improved with the removal of any single item. For the TPS 15-17 Version ( $n = 42$ ), ordinal  $\alpha$  values were as follows: overall scale (ordinal  $\alpha = 0.93$ ), Knowledge subscale (ordinal  $\alpha = 0.93$ ), Skill subscale (ordinal  $\alpha = 0.87$ ), and Taking Charge subscale (ordinal  $\alpha = 0.71$ ). Examination of changes in ordinal  $\alpha$  values when individual items were removed from the TPS 15-17 Version indicated that the internal consistency of the overall scale would improve slightly (ordinal  $\alpha = 0.94$ ) with the removal of the fourth item of the Taking Charge subscale ("It is important for me to have an adult doctor."). Similarly, the internal consistency of the Knowledge subscale would improve slightly (ordinal  $\alpha = 0.94$ ) with the removal of the third item of the subscale ("I know my medical providers or specialists."). As the TPS 15-17 Version overall scale and Knowledge subscale demonstrated high internal consistency and as the improvement in internal consistency with item removal was slight, no items were removed from the measure.

## Testing Hypothesis 2: Validity of the TPS.

The concurrent and convergent validities of each version of the TPS were determined by conducting bivariate analyses testing the relationship between the percentages of TPS (or TPS subscale) items endorsed at the “Yes! I can do this” level and other measures related to TR. If a patient completed the same version of the TPS more than once, then the responses from the most recent administration were included in analyses for that version of the TPS, so that no patient was represented more than once.

**Concurrent validity.** I assessed concurrent validity through calculating the bivariate correlations between pairs of TPS subscales. The subscale scores of the TPS 18+ Version ( $n = 110$ ) were positively correlated. The Knowledge and Skill subscales’ scores exhibited the strongest correlation ( $r = 0.593, p < 0.001$ ). The Knowledge and Taking Charge subscales’ scores were weakly correlated ( $r = 0.226, p = 0.02$ ), and the Skill and Taking Charge subscales’ scores were moderately correlated ( $r = 0.360, p < 0.001$ ). These results suggested that the subscales of the TPS 18+ Version were measuring related but somewhat different aspects of the TR construct, supporting the concurrent validity of the TPS 18+ Version.

Among the TPS 15-17 Version subscales ( $n = 42$ ), the Knowledge and Skill subscales’ scores were positively correlated ( $r = 0.775, p < 0.001$ ). Neither the Knowledge nor the Skill subscales’ scores were significantly correlated with the Taking Charge subscale scores. These results suggested that patients’ perceptions of their healthcare-related knowledge and of their health-management skills were closely related for patients in the 15-17-year-old age group. Patients’ attitudes toward independent health management and transitioning to an adult-care provider appeared unrelated to their perceptions of knowledge and health-management skills. Support for the concurrent validity of the TPS 15-17 Version appeared mixed, though further

evaluation may be warranted, as the subsample of patients who completed this version was limited ( $n = 42$ ).

Please see Table 8 for a full summary of the correlations among the subscale scores of the TPS 18+ Version and the TPS 15-17 Version.

**Convergent validity.** I assessed convergent validity through calculating bivariate correlations between TPS scores (overall and individual subscale scores) and factors that have been explored in the literature as being related to transition readiness or transition outcomes. I also compared the TPS scores of subgroups of patients who were at lower or higher risk for neurocognitive difficulties that may affect independent functioning.

The TPS 18+ Version's total scores ( $r = 0.213, p = 0.03$ ) and Skill subscale's scores ( $r = 0.274, p = 0.004$ ) were positively correlated with patient age at the time of TPS administration ( $n = 110$ ). This small, positive correlation suggested that patient readiness to transition increased with age, which could reflect the effects of general maturation on self-perceived independence with health management. The Taking Charge subscale's scores were negatively correlated with the number of transition clinic appointments attended ( $r = -0.203, p = 0.04$ ), and the Knowledge subscale's scores were negatively correlated with the percentage of transition clinic appointments attended ( $r = -0.204, p = 0.03$ ). These findings were counterintuitive, as it had been expected that higher levels of engagement in transition preparation services would have led to increased independence with health management. TPS scores were not significantly correlated with the general attendance rate for outpatient pediatric appointments or with the number of appointments attended when healthcare transition issues were directly discussed. Please see Table 9 for a detailed summary of correlations between the TPS scores and factors related to transition readiness.

Comparisons of TPS scores of patients at lower and higher levels of risk for neurocognitive difficulties were conducted using one-tailed independent *t* tests, as patients at lower risk were expected to have higher TPS scores. Results indicated that patients who were not diagnosed with any neurocognitive or neurodevelopmental disorders ( $n = 71$ ) had higher TPS 18+ Version total scores ( $t(39774.502) = 3.296, p < 0.01$ ), Knowledge subscale scores ( $t(28771.541) = 2.881, p < 0.01$ ), and Skill subscale scores ( $t(17589) = 3.327, p < 0.01$ ) than patients with one or more diagnoses ( $n = 39$ ). (Note that the multiple imputation technique produced the pooled estimates of *t* scores that were reported.) Additionally, for patients who were eighteen years and older ( $n = 106^1$ ), those without legal guardians ( $n = 100$ ) had considerably higher TPS 18+ Version total scores ( $t(10607) = 6.063, p < 0.01$ ) and subscale scores (Knowledge,  $t(48879) = 5.365, p < 0.01$ ; Skill,  $t(2019) = 4.385, p < 0.01$ ; Taking Charge,  $t(1489) = 3.180, p < 0.01$ ) compared to those with legal guardians ( $n = 6$ ). TPS scores were not significantly higher for cancer survivors whose cancer or treatment did not affect their central nervous systems compared to those of cancer survivors whose central nervous systems were affected. Please see Table 10 for a detailed summary of the mean TPS scores for each patient subgroup and results of the one-tailed independent *t* tests. The associations between the TPS 18+ Version and patient age, diagnosis of neurocognitive or neurodevelopmental disorders, and involvement of a legal guardian for adult patients provided support for the measure's convergent validity.

The TPS 15-17 Version scores were not found to correlate with age at TPS administration, the indicators of patient involvement in transition preparation services, or general attendance rates for outpatient pediatric appointments. Please see Table 9 for a detailed

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<sup>1</sup> Four respondents to the TPS 18+ Version were younger than 18-years-old and had been administered the wrong version.

summary of these correlations. Cancer survivors whose cancer or treatment did not affect their central nervous systems did not have significantly higher TPS scores compared to cancer survivors whose central nervous systems were affected. Patients who were not diagnosed with any neurocognitive or neurodevelopmental disorder did have higher TPS 15-17 Version total scores ( $t(54832) = 2.098, p = 0.02$ ), Knowledge subscale scores ( $t(48227) = 1.987, p = 0.02$ ), and Skill subscale scores ( $t(13521) = 2.142, p = 0.02$ ) compared to those with one or more diagnoses. Please see Table 10 for a detailed summary of the mean TPS scores for each patient subgroup and results of the  $t$  tests. Results indicated tentative support for the convergent validity of the overall TPS 15-17 Version measure, the Knowledge subscale, and the Skill subscale. Results did not support the convergent validity of the TPS 15-17 Version's Taking Charge subscale.

### **Follow-up Phone Survey Results**

As only nine individuals provided information regarding transition outcomes, hypotheses related to the TPS's predictive validity and related to potential socio-demographic, medical, and pediatric and transition preparation services engagement predictors of transition outcomes could not be tested quantitatively. Descriptions of the phone survey respondents' transition outcomes, their levels of satisfaction with the transition process, and their qualitative feedback regarding the transition process are provided below.

**Healthcare transition outcomes and satisfaction ratings.** Quantitative results from the follow-up phone survey are summarized in Table 11. The nine survey completers ranged in age from 22.5 year to 26.6 years ( $M(SD) = 24.2 (1.3)$  years) at the time they completed the phone survey. Five of the survey completers (55.6%) had successfully transitioned to an adult primary care provider, as they had attended at least one adult primary care appointment within one year after their last transition clinic appointment at CMH and they had attended, on average, one or

more adult primary care appointments per year after transitioning out of pediatric care. Three of the survey completers (33.3%) had been partially successful in their transition to an adult primary care provider. These three individuals did not attend any adult primary care appointments during their first year after transitioning out of pediatric care, though they eventually did establish care with an adult primary care provider after 1-2 years. One survey completer indicated that care had not been established with an adult primary care provider during the two years since her transition out of pediatric care.

Of the nine survey completers, seven had received recommendations from their pediatric providers at CMH to engage in specialty medical care with adult-care providers. Three of these individuals (42.9%) had successfully transitioned to adult specialty care. These individuals had attended one or more appointments within each type of adult-care medical specialty service that had been recommended within the first year since transitioning out of pediatric care. The other four individuals (57.1%) had been partially successful in their transition to adult specialty care. These individuals had attended one or more appointments within at least one but not every type of adult-care medical specialty service that had been recommended within the first year since transitioning out of pediatric care.

The survey completers were asked to rate their overall satisfaction with the healthcare transition process on a 6-point Likert scale ranging from 0 (*entirely dissatisfied*) to 5 (*entirely satisfied*). Six of the nine survey completers indicated that they were *moderately satisfied* with the transition process, while two indicated that they were *entirely satisfied* and one indicated being *mildly satisfied*.

**Feedback on the healthcare transition process.** At the end of the phone survey, the young adults were asked in an open-ended manner for suggestions for improving the healthcare

transition process. The survey completers' responses included expressions of appreciation for the assistance they received from healthcare providers throughout their own transition experience and reflections on the difficulties they encountered during their transition process, as well as suggestions. Their responses are summarized below to provide examples of transition clinic services that were perceived as especially helpful, barriers that were experienced in the transition process, and aspects of the transition process that the young adults perceived could be improved.

Eight of the nine survey completers explicitly expressed appreciation for the resources provided by the CMH Survive and Thrive Clinic. Resources mentioned specifically included the cancer treatment summaries, the care plans individualized to a patient's cancer and treatment history (i.e., information about the types of adult-care medical specialists recommended for an individual patient, the types and frequencies of medical tests needed), and scholarship information for cancer survivors. One survey completer indicated that after attending the Survive and Thrive appointments, "I felt like I knew what to do next." Three of the survey completers expressed appreciation for the adult-care providers to whom they transitioned after leaving CMH. One individual specifically mentioned appreciating how an adult-care clinic had called her to schedule her first appointment with them.

Four of the nine survey completers mentioned specific difficulties they had encountered in the transition process. Two survey completers reported difficulties with changes in health insurance – one individual reported being "unexpectedly dropped" from her parents' insurance, and the other individual reported challenges with changing her health insurance policy when she turned 26-years-old. Both indicated that the insurance change was a significant barrier to accessing primary care services. One of the two individuals reported that, while she received assistance from the Survive and Thrive Clinic with obtaining a new "Obamacare" health



insurance plan, she had difficulty finding primary care providers who accepted her new insurance plan or who had openings for new patients. A third survey completer described a different type of transition-related difficulty, as an out-of-state primary care provider did not appear to understand her need for continued cancer survivorship follow-up care, even though she had shared her pediatric medical records, cancer treatment summary, and individualized survivorship care plan with the primary care provider. This individual mentioned receiving support from a regional Cancer Care Alliance to advocate for the types of services and referrals to specialists indicated in her individualized care plan. A fourth survey completer described how she had experienced difficulties related to her medical device, as she had received a hearing aid from CMH that could not be tested at her adult-care audiologist's clinic due to incompatibility.

Five of the nine survey completers provided suggestions for improving the healthcare transition process based on how they would have wanted to change their own transition experiences. One individual indicated that she would have preferred to receive names of specific adult-care specialists in her area from her pediatric medical team, as she described her experience of searching for an appropriate specialist as complicated, even with assistance from a parent. This individual also reported that she would have preferred to transition to adult care at eighteen years of age instead of twenty-one years of age, as she had felt ready to transition at that earlier time and would have preferred more time to "get used to" adult care services. Another individual suggested that it would be helpful to receive a one-year post-transition follow-up call from the CMH transition clinic to verify whether or not the young adult had made a first appointment with an adult primary care provider. She stated, "I know this is my responsibility but it would be helpful to know someone was going to follow-up and remind me." A third survey completer suggested that more follow-up from the CMH transition clinic on records

transfer to adult-care providers would have been helpful. This individual also indicated that a demonstration of how a patient could access his or her own medical records or treatment summary would have been helpful. A fourth survey completer indicated wanting more information at the pre-transfer stage on possible late effects of cancer, helpful dietary guidelines, and sources of support as well as a greater emphasis on quality of life issues in patient-provider communication. She also commented on wanting more nuanced communication regarding risk for infertility. She described her pediatric providers as conveying a strong message that she would not be able to conceive without fertility interventions, given her cancer treatment history, while she found she was able to conceive without interventions. A fifth survey completer indicated wanting additional written resources on health-related topics at the pre-transfer stage, as she later received helpful books and brochures from an adult-care clinic.

Additional comments provided by the survey completers indicated that two individuals had formed close relationships with their adult-care specialty providers. One individual reported that her “adult endocrinologist was kind of like my primary care physician because I see him regularly and he received all my CMH records.” The other individual indicated that she appreciated being able to see one adult specialist consistently in contrast to seeing multiple providers within a specialty clinic at CMH. A third survey completer provided the following advice for young adults in the transition process: “keep up with your medical records and medical history; and make sure you’re comfortable with the adult doctor.”

### **Discussion**

One purpose of this study was to evaluate the psychometric properties of the TPS, a generic (not condition specific) TR measure developed for clinical use in specialty healthcare transition clinics within a large children’s hospital. Two of the three versions of the TPS were

evaluated – the TPS 18+ Version and the TPS 15-17 Version. This initial evaluation indicated that the TPS 18+ Version was comparable in terms of its content and psychometric properties to the TR measures described in the HCT literature. Similar to existing TR measures, the TPS items covered aspects of TR related to self-management of one’s disease or condition (e.g., knowledge about condition and treatments/medications, taking medications independently, refilling prescriptions), self-management of one’s general health (e.g., keeping medical records, recognizing emergency health situations, taking responsibility for healthcare), self-advocacy (communication with healthcare providers, managing transportation for medical appointments), insurance knowledge, perceptions and attitudes toward transition, and perception of social support. TPS item development was influenced by pre-existing TR measures. Item refinement was based on feedback from multiple stakeholders including patients, family members, pediatric clinicians, and hospital personnel involved in patient advocacy and family centered care. The TPS 18+ and 15-17 Versions required an eighth-to-ninth grade reading ability, which was somewhat high compared to existing TR measures for which the reading levels were reported in the literature. The processes by which the TPS was initially developed grounded it in the HCT research literature and reflected sensitivity to the practical use of the TPS in the clinical setting.

The overall TPS 18+ Version and its three subscales demonstrated adequate internal consistency, and this was comparable to TR measures described in the literature. Weak-to-moderate correlations among the three subscales provided support for the TPS 18+ Version’s concurrent validity and suggested that each subscale was measuring different but related facets of TR. Results also indicated preliminary support for convergent validity. The TPS 18+ Version’s total scores and the Skill subscale scores correlated positively with patient age. Additionally, the total scores, Knowledge subscale scores, and Skill subset scores were

significantly higher for patients having lower risk for neurocognitive difficulties compared to patients having diagnoses of one or more neurocognitive or neurodevelopmental disorders and compared to patients having legal guardians in adulthood. Examination of the TPS 18+ Version's convergent validity indicated that the TPS's relationships with patient age and with risk for neurocognitive difficulties were similar to the relationships of existing TR measures with these patient variables. This study's ability to assess the predictive validity of the TPS 18+ Version was significantly limited by the small number of patients for whom transition outcome data were obtained. More data would need to be collected to evaluate the measure's predictive validity. This initial evaluation of the TPS 18+ Version indicated that the measure demonstrated adequate reliability and preliminary evidence for validity, though criterion validity would need to be further established through demonstrating the relationship between the TPS and external measures of TR and the predictive relationship between the TPS and HCT outcomes.

In evaluating the TPS 18+ Version's convergent validity, several analyses yielded counterintuitive or unexpectedly non-significant results. It had been expected that TR would have increased with increasing engagement in transition preparation services. However, the Taking Charge subscale scores and the Knowledge subscale scores were negatively correlated with the number and percentage of transition clinic appointments attended, respectively. Potential explanations for these findings included the possibility that more transition clinic appointments were needed for the patients who required greater assistance with preparing for the transition, or the patients who had attended more transition clinic appointments had more awareness of what transition preparedness entailed and were less likely to overestimate their knowledge, skills, and readiness to transition. Results indicated that TPS scores and overall engagement in pediatric services (i.e., percentage of scheduled appointments at a pediatric

hospital that were attended) were unrelated. A potential explanation may have been that engagement in pediatric services reflected factors unrelated to the patient's self-management skills (e.g., parents' ability to manage their child's care, family chaos, difficulty managing appointments in multiple clinics for medically complex patients). Results also indicated that TPS scores were not higher for cancer survivors whose central nervous systems were unaffected by their disease or treatment compared to those whose central nervous systems were affected. Perhaps this finding reflected how diagnosis of neurocognitive disorders (including cancer treatment-related late effects), rather than cancer-related central nervous system involvement, served as a better indicator of risk for neurocognitive difficulties that could negatively affect self-management.

Evaluation of the TPS 15-17 Version indicated adequate internal consistency of the overall measure and its three subscales. Concurrent validity was supported by a strong correlation between the Knowledge and Skill subscales. However, the Taking Charge subscale was not found to be related to the other subscales. Support for convergent validity was limited: the overall TPS 15-17 Version scores and scores for the Knowledge and Skill subscales were significantly higher for patients having lower risk for neurocognitive difficulties compared to patients having diagnoses of one or more neurocognitive or neurodevelopmental disorders. However, the TPS 15-17 Version's scores were unrelated to patient age and engagement in pediatric and transition preparation services. The non-significant correlation between the TPS 15-17 Version's scores and patient age at administration was likely due to a restriction of the age range of patients included in the study. As the current study had focused on patients who were more likely to have transitioned before the study's data collection phase, only patients who were seventeen-years-old when last administered the TPS were included in the analysis of the TPS 15-

17 Version. Predictive validity of the TPS 15-17 Version was not assessed as this was not the version of the TPS administered at the last transition clinic appointment for the patients who provided information regarding transition outcomes. This initial evaluation of the TPS 15-17 Version indicated that the measure demonstrated adequate reliability and limited evidence for the validity of the overall measure, the Knowledge subscale, and the Skill subscale. However, this initial evaluation was limited by the relatively small sample size ( $n = 42$ ) and restrictions in variation within the sample.

The relationships among the subscales appeared to function differently within the TPS 15-17 Version compared to the TPS 18+ Version. While the TPS 18+ Version's subscales appeared to measure related but different constructs, the TPS 15-17 Version's Knowledge and Skill subscales may be measuring the same construct as they were strongly correlated, and the TPS 15-17 Version's Taking Charge subscale appeared unrelated to the other subscales or to risk for neurocognitive difficulties. Further evaluation of the TPS 15-17 Version's validity should be conducted on a larger sample. Additionally, further refinement of the TPS measures should include a factor analysis to determine whether the factor structures confirm the current organization of the TPS by its subscales and to determine if the versions of the TPS differ in their factor structures. It could be the case that, for adolescent patients, competency with transition-related skills is more strongly dependent on knowledge, while for the young adult patients (eighteen-years-old and older), there may be a more meaningful difference between medical condition knowledge and ability to complete health management tasks independently.

A second purpose of this study was to evaluate predictors of transition outcomes. While the low number of individuals who provided information about transition outcomes did not support the quantitative evaluation of transition outcome predictors, the qualitative information

gathered through the follow-up phone surveys may help inform future investigations of factors influencing transition outcomes. In particular, survey completers' reports suggested that continuity and adequacy of health insurance coverage in young adulthood, receipt of referrals to specific adult-care specialists, parental support through the transition process, and patient self-perception of TR may be important factors to continue investigating. Additionally, as multiple survey completers had reported barriers faced within the transition process that they needed to overcome, investigation of young adults' general self-advocacy and problem-solving skills may also be important.

### **Limitations**

Several limitations of this study were associated with the retrospective collection of data through the medical record review portion. The options for measures used in the evaluation of the TPS's validity were limited to the information recorded in the medical record for clinical uses. This limitation especially affected assessment of the TPS's concurrent validity, as no additional measure of TR was routinely described in the medical records. Some of the patients' medical records had included indications of whether a patient was able to provide a three-sentence summary of his or her medical history and treatment. While these indications could provide a behavioral criterion against which the TPS scores could be compared, this information was not systematically reported in the patients' medical records within all the transition clinics.

Due to the nature of the retrospective medical record review, attempts to recover missing data could not be made. Specifically, there was no opportunity to ask patients included in the medical record review portion of the study to provide response clarification when they had either left a TPS item unanswered or had provided multiple responses to a TPS item. Although multiple imputation of missing values was supported by evidence of a Missing At Random

mechanism of missingness, imputation of missing TPS values based on responses to other TPS items may have artificially inflated the internal reliability of the measure and its subscales.

An additional limitation associated with the study's partly retrospective design was the lack of opportunity to administer the TPS to patients who did not receive transition preparation services and to measure their transition outcomes. Patients who did not receive transition preparation services could have been patients treated within the same CMH medical specialty services as the patients who were included in this study but who did not participate in the transition clinics, or they could have been patients treated within other medical specialty services (within CMH or at a different hospital) that did not have formalized transition preparation services. It is possible that patients who did not receive transition preparation services would have provided meaningfully different responses to the TPS during the pre-transfer period, faced different types of barriers to successful transition, and experienced a different distribution of transition outcomes compared to those who did participate in the transition clinics. As this study was unable to include these patients, the possibility of restriction in the ranges of socio-demographic factors, medical characteristics, levels of service engagement, TPS scores, and transition outcomes must be acknowledged.

Other limitations of this study were associated with the subsample sizes of individuals who completed the TPS 15-17 Version and of individuals who completed the follow-up phone survey. The subsample of patients who completed the TPS 15-17 Version at their last transition clinic prior to January 1, 2015 was limited by the targeting of individuals who were most likely to have transitioned to adult care by the time of this study's data collection period (i.e., those eighteen-years-old and older by January 1, 2015) and by the restriction of including only the most recently administered TPS into analyses so that individuals were not represented more than



once in analyses. Restrictions in both the subsample size ( $n = 42$ ) and age range represented within the subsample (only seventeen-year-old individuals) limited the interpretation of analyses evaluating the TPS 15-17 Version's psychometric properties. The small number of survey completers precluded quantitative evaluation of the TPS 18+ Version's predictive validity as well as the development of an empirically-derived model of HCT outcomes predictors.

In addition to the restricted subsample size, challenges with measuring transition outcomes represented another study limitation. One challenge involved the limitations of patient self-report of adult-care appointments attended since transitioning out of pediatric care. While some of the young adults indicated that they were reviewing records of their adult-care appointments when completing the survey, others provided rough estimates of when they had attended these appointments. Inaccuracy and imprecision of reporting on these appointment dates likely resulted in some error in determining the classification of transition outcomes. I had attempted to survey the adult-care providers to verify the accuracy of the young adults' recall of appointments, as well as to receive their feedback on the transition process. However, as it was rarely the case that I was able to communicate directly with the adult-care clinicians and as their office staff may have been unfamiliar with research studies generally or misunderstood the specifics of what was requested regarding this particular study, the adult-care provider survey completion rate was very low and the information could not be included in analyses.

Another challenge in measuring transition outcomes involved the identification of which specialty services a patient was recommended to see in adult care. While I made determinations of the outcomes related to transition to adult-care specialists based on the types of adult-care specialty services recommended in the pediatric medical record notes, some of the survey completers indicated that they were not receiving a type of adult specialty care because they did

not need it. Additionally, some survey completers indicated that they were receiving a type of adult specialty care that had not been recommended by the pediatric transition clinic team but that had been recommended by their adult primary care provider. It is possible that survey completers reported not needing a previously recommended adult-care specialty service due to forgetting the recommendation (corresponding to unsuccessful transition) or due to their adult primary care provider's determination that the adult specialty service was not needed (in which case transition to that type of specialty care would not be necessary). Any attempt to operationalize types of outcomes for transition to adult specialty care would likely be challenged to reflect the variations in how successful transition may be experienced by young adults, as input from both the pediatric medical team and the adult primary care provider shape these experiences. For research purposes, it would likely be best to focus on transition to adult primary care services when studying predictors of transition outcomes and/or transition to one type of specialist to which all patients with a particular condition would be referred.

### **Future Directions**

This study has provided strong initial support for the reliability of the TPS 18+ and 15-17 Versions. This study has also provided preliminary support for the validity of the TPS 18+ Version as well as some qualified support for the TPS 15-17 Version's validity. Both versions of the TPS would benefit from further development. Confirmatory factor analyses conducted on TPS responses gathered from larger samples would determine whether the TPS subscales were consistent with the measure's factor structure and clarify whether or not the different versions of the TPS had similar factor structures. Administering parallel versions of the TPS to patients' parents or caregivers in addition to administering the TPS to the patients would allow the measure's interrater reliability to be determined. Similarities in patients' and parents' ratings

would suggest reliable measurement of TR, while discrepancies could provide clinically useful information to the pediatric transition clinic teams and indicate the need to explore the differences in patients' and parents' perceptions with the families. Determining the test-retest reliability of the TPS and then testing the measure's sensitivity to detecting meaningful changes in TR would provide an empirical basis for justifying the use of the TPS as a measure of individuals' responsiveness to transition preparation interventions.

Further development of the TPS would need to include additional assessment of the measure's concurrent and predictive validities. While the concurrent validity of a measure under development is best evaluated by comparison to an established measure of the target construct, no gold standard measure for TR has been established. Reviews (Schwartz et al., 2014; Zhang et al., 2014; this author's review) of TR measures described in the research literature indicated that these measures were "promising" or "approaching well-established" at best, per EBA criteria. The best option may be to measure concurrent validity by comparing responses on the TPS to behavioral demonstrations of patients' transition-related knowledge or competence with transition-related skills. Measures of demonstrated knowledge or skills could include clinician ratings of patients' responses to health-related questions (e.g., rating the percentage of one's outpatient medications for which the patient was able to name, describe the dosage and frequency of dosing, and describe the purpose; rating the accuracy with which a patient completes a standard medical history form or provides a three-sentence summary of his or her medical condition and treatments), parent ratings of patients' demonstrations of health-management skills (e.g., rating the percentage of injection medication doses that a patient correctly administers independently and within the correct time frame per month), or clinician or parent ratings of patients' completion of transition skills "homework assignments" (e.g., write

down three questions and ask those questions to your physician during the next appointment; call your pharmacy or use an online refill form to request the next refill for your medications and pick up the filled prescription; set up your next appointment with a primary care or specialty care clinic; call your health insurance provider to ask a question about your benefits).

Although the current study attempted to evaluate the predictive validity of the TPS 18+ Version, the small number of follow-up survey completers restricted ability to perform quantitative analyses. With a larger number of individuals providing information related to transition outcome, both predictive validity and incremental validity of the TPS should be evaluated. Options for obtaining follow-up information from a larger number of individuals who have transitioned out of pediatric care include expanding the current study to identify and contact patients who concluded their pediatric care at CMH after January 1, 2015 and/or collaborating with other pediatric hospitals to conduct a multi-site study using the TPS. Additionally, adjustments to the method for collecting follow-up information could be considered. Specifically, transition clinics may consider incorporating post-transition follow-up into their clinical procedures. Two of this study's follow-up survey completers had indicated that they would have appreciated some form of follow-up from the pediatric transition clinic about one year following their last CMH appointment. Transition clinics may consider introducing the idea of a one-year post-transfer follow-up call to patients and their families during one of their last transition clinic appointments. The clinical purposes of the call could include helping young adults overcome barriers encountered in the transition process, assisting with any concerns about records transfer, and reinforcing young adults for successful transitions or efforts made toward establishing adult care. When the follow-up call is introduced, patients could be offered the opportunity to consent to the inclusion of information from the follow-up call in a research

database. Obtaining research consent before the transition, pairing the collection of data for research with a clinical service that young adults may find valuable, and roughly scheduling the follow-up phone calls may increase the young adults' response rate to follow-up surveys.

The current study had attempted to obtain an objective count of post-transition adult-care appointments through surveying the adult-care primary and specialty care providers. Future studies should continue to seek information regarding transition outcomes from adult-care providers to verify the accuracy of patient self-report. However, the approach for requesting this information from adult-care providers should be simplified. The response rates of adult-care clinics may increase if the clinics are asked to provide medical records for the identified young adults instead of requesting that a representative from the adult-care clinic complete a phone or online survey. The limitation to requesting only medical records would be the loss of information regarding the adult-care providers' experience of the transition process or their suggestions for improvement.

Increasing sample size and including individuals who had not participated in a pediatric transition preparation program would contribute to the literature on empirically determined transition outcome predictors. In addition to socio-demographic factors, medical characteristics, engagement in pediatric and transition preparation services, and transition-related self-management competencies, future studies may also consider evaluating continuity and adequacy of insurance coverage in young adulthood, competence with self-advocacy and problem-solving, and parental involvement as potential predictors of transition outcomes. A few of this study's survey completers mentioned facing challenges related to managing health insurance changes as well as advocating for adult medical services recommended by the pediatric transition clinic team. It could be that general self-advocacy skills may predict ability to overcome these barriers

to transition. The investigation of parental involvement would help clarify the extent to which parental involvement in a patient's health-management activities needs to decrease to support the patient's increasing independence (as in the transition models proposed by While and colleagues (2004)) and the extent to which parental involvement throughout the transition process may facilitate a successful transition outcome. One of this study's survey completers received assistance from her mother in reporting adult-care appointment dates, suggesting continued parental involvement with managing these appointments or the patient's records of appointments, and another survey completer had mentioned receiving help from her father to find adult-care providers. As the transition process and the factors influencing it are complex, continuing research in this area will need to strongly consider multi-site studies and ways of designing longitudinal studies that can be easily incorporated into the clinical procedures of pediatric clinics and transition preparation clinics.

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Table 1. Summary of Transition Readiness Measures' Development, Characteristics, and Psychometric Properties

TR Measure	Sample	Development	Characteristics	Psychometric Properties
Am I ON TRAC for Adult Care Questionnaire, youth and parent versions	N = 200 patients N = 191 parents Ages: 12-18 years	<i>Item construction</i> HCT literature and HCT programs review, expert review (HCPs) of transition indicators	Generic (not condition-specific) measures 25 patient (and parent) SR items  <i>Subscales (number of items)</i> Knowledge scale (16 with 2 unscored); Behaviour index (9)	<i>Internal consistency</i> Knowledge scale (Cronbach's $\alpha = 0.84$ )  Behaviour index not expected to measure unitary construct
Moynihan, 2012; Moynihan, Saewyc, Whitehouse, Paone, & McPherson, 2014; ON TRAC program (British Columbia Children's Hospital <a href="http://ontracbc.ca/">http://ontracbc.ca/</a> )	Conditions: cardiac (54), diabetes (72), gastroenterological disorders (54), and neurological disorders (20)	<i>Measure refinement</i> EFA results informed modification and removal of items	<i>Item response format</i> Knowledge scale: 4-pt Likert (1 = <i>strongly disagree</i> , 4 = <i>strongly agree</i> ); Behaviour index 5-pt Likert (1 = <i>never</i> , 5 = <i>always</i> )  <i>Scoring</i> Knowledge scale: sum item responses (range: 14-56); Behaviour index: sum item responses (range: 9-45) or count behaviors performed above theoretical threshold frequency (range: 0-9)	<i>Interrater reliability</i> Knowledge scale: patients' and parents' scores ( $r = 0.26$ )  Behaviour index: patients' and parents' scores ( $r = 0.32$ )  <i>Validity</i> Knowledge scale: Concurrent (Behaviour index); Convergent (age, psychosocial maturity); EFA supported single factor scale
Copies of original and revised measure available in Appendices C and E of Moynihan, 2012				Behaviour index: Concurrent (Knowledge scale); Convergent (age, psychosocial maturity, gender)
California Healthy and Ready to Work (CA HRTW) Transition Health Care Assessment Tool	N = 25 Ages: 14-21 years Conditions: acquired neurological condition (4), cancer (8), congenital anomalies (3); SB, craniofacial anomaly, developmental disabilities (7); MR, epilepsy, CP, Tourette's), IBD (1), and SCD (2)	<i>Item construction</i> Checklist of competencies/skills for achieving self-sufficiency informed by theories of development and self-care  <i>Measure refinement</i> Examination of N/A responses informed removal of one item	72 patient SR items  <i>Subscales abbrev. (number of items)</i> Knowledge of health condition/ management (5); Preventative health behaviors (9); Emergency measures (6); Environmental modifications/ accommodations (4); Monitor health condition (3); Manage SHCN (6); Communicate effectively (4); Community resources (4); Responsible sexual activity (4); Reproductive counseling (4); Track health records (4); Health insurance (2); Legal rights and protections (4); Transportation (13)  <i>Item response format</i> Responses coded 1 = <i>Yes or with assistance</i> , 0 = <i>No</i> , or <i>N/A or unknown</i>	<i>Internal consistency</i> Subscales Kuder-Richardson $\alpha$ range: 0.00-1.00 (8 subscales with $\alpha > 0.60$ )  <i>Validity</i> Concurrent (Higher % <i>Yes</i> for patients with cancer compared to patients with developmental disabilities)
Betz, 1998; Betz, 2000; Betz, Redcay, & Tan, 2003				
Request a copy from Cecily Betz, Ph.D. (cbetz@usc.edu)				

*Scoring*  
% *Yes* responses; % *No* responses

TR Measure	Sample	Development	Characteristics	Psychometric Properties
Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen)	N = 1533 Ages: 10-19 years Recruited from pediatric private practice primary care clinic, 5 middle schools, 3 high schools, and 2 summer programs	<i>Item construction</i> Modeled after the Rapid Estimate of Adult Literacy in Medicine (REALM); words selected from American Academy of Pediatrics patient materials	66-item word-recognition test  <i>Item response format</i> Patient reads each word aloud, and administrator rates accuracy of pronunciation (“+” = correct, “-” = incorrect, “.” = not attempted)  <i>Scoring</i> Number of words pronounced correctly: 0-37 (3 <sup>rd</sup> grade or lower reading level), 38-47 (4 <sup>th</sup> -5 <sup>th</sup> grade), 48-58 (6 <sup>th</sup> -7 <sup>th</sup> grade), 59-62 (8 <sup>th</sup> -9 <sup>th</sup> grade), 63-66 (10 <sup>th</sup> grade and higher)	<i>Internal consistency</i> Cronbach’s $\alpha = 0.94$  <i>Test-retest reliability</i> Correlation between scores separated by 1-week period ( $r = 0.98$ )
Davis et al., 2006 Request a copy from Cristalyn Reynolds (creyn1@lshsc.edu)				<i>Validity</i> Criterion (Wide Range Achievement Test-Revised, Slosson Oral Reading Test-Revised)
Self-Management Skills Assessment Guide, youth and parent versions Williams et al., 2010 Items listed in Table 2; Request copies from Tricia Williams, Ph.D. (tricia.williams@sickkids.ca)	N = 49 patients N = 49 parents Ages: 11-19 years Conditions: acquired brain injury (5), cardiac (4), CP (3), chronic daily headaches (2), chronic pain (4), epilepsy (21), gastrointestinal (5), rheumatology (4), SB (1)	<i>Item construction</i> Items selected from previous TR measures based on definition of medical self-management	21 patient (and parent) SR items  <i>Item response format</i> 5-pt Likert scale (1 = <i>strongly disagree</i> , 5 = <i>strongly agree</i> )  <i>Scoring</i> Total score = mean (or median) of individual item scores (range: 1-5)  <i>Readability</i> Flesch-Kincaid Grade Level: youth version (4.9), parent version (5.9)	<i>Internal consistency</i> Cronbach’s $\alpha = 0.89$ (youth), 0.93 (parent)  <i>Interrater reliability</i> Correlation between youths’ and parents’ scores ( $r = 0.54$ )  <i>Validity (for both youth and parent-report)</i> Concurrent (higher scores for youth in transition program vs. neurology patients); Convergent (general independence)
STARx Transition-Readiness Survey Ferris et al., 2013; STARx Program (Univ. of North Carolina – Chapel Hill <a href="http://www.med.unc.edu/transition/transition-tools">http://www.med.unc.edu/transition/transition-tools</a> ) Copy of Version 4 available on STARx Program website	Adolescents with chronic conditions attending transition program Ages: 12-24 years	<i>Item construction</i> Patient focus groups and interviews (concurrent think-aloud technique), review of existing HCT checklists, interdisciplinary collaboration among public health students, Stages of Change Model	18 patient SR items  <i>Item response format</i> 5-pt Likert scales: Items assessing frequency of behavior (1 = <i>never</i> , 5 = <i>always</i> ); Items assessing knowledge (1 = <i>nothing</i> , 5 = <i>a lot</i> ); Items assessing ease of behavior (1 = <i>very hard</i> , 5 = <i>very easy</i> )  <i>Scoring</i> Not reported	<i>Reliability</i> Not reported  <i>Validity</i> EFA supported 5 domains of survey items (self-management, self-efficacy, medication adherence, disease knowledge, and medication strategies)

TR Measure	Sample	Development	Characteristics	Psychometric Properties
Transition Readiness Assessment Questionnaire (TRAQ)	N = 192, Version 1; N = 305, EFA sample N = 221, CFA sample Ages: 14-26 years	<i>Item construction</i> Stages of Change/ Trans theoretical Model, combined items with common subject from review of existing TR measures	20 patient SR items (TRAQ 5.0)  <i>Subscales (number of items)</i> Appointment keeping (7), Tracking health issues (4), Managing medications (4), Talking with providers (2), Managing daily activities (3)  <i>Item response format</i> 5-pt Likert corresponding to Stages of Change (1 = <i>I do not need to do this</i> (pre-contemplation), 5 = <i>I always do this when I need to</i> (maintenance))  <i>Scoring</i> Total = sum of item responses (range: 20-100)	<i>Internal consistency</i> Total score Cronbach's $\alpha$ range: 0.93-0.94; Subscales Cronbach's $\alpha$ range: 0.67-0.90  <i>Test-retest reliability</i> Correlation between scores separated by 4-week period ( $r = 0.81$ , version 1)
Sawicki et al., 2011; Wood et al., 2014; <a href="http://hscj.ufl.edu/jaxhats/traq/">http://hscj.ufl.edu/jaxhats/traq/</a>	Conditions: Activity limiting physical condition (e.g., CP, chronic pulmonary disease, CHD, CF, deafness, diabetes, SCD, SB, spinal cord injury); Cognitive impairment (ASD, mild mental retardation); Mental health disorder (ADHD, behavioral disorder, bipolar disorder, learning disorder)	<i>Measure refinement</i> Feedback from patients and HCT experts, EFA, and pattern of missing responses informed modification and elimination of items		<i>Validity</i> Concurrent (higher scores for patients with activity-limiting conditions vs. patients with cognitive impairments or mental health disorders, version 1); Convergent (age); CFA verified excellent fit of 5-factor model

TR Measure	Sample	Development	Characteristics	Psychometric Properties
UNC TRxANSITION Scale™	N = 92, Version 1; N = 36, Version 2; N = 128, Version 3	<i>Item construction</i> Theoretical foundation (learning principles, self-determination theory), HCT literature and program websites review, interviewed HCT experts, items written for 10 conceptual domains	33 clinician administered and rated interview items <sup>2</sup> (version 3)  <i>Subscales (number of items)</i> <u>T</u> ype of chronic health condition (3), <u>R</u> x/medications (4), <u>A</u> dherence (3), <u>N</u> utrition (3), <u>S</u> elf-mgmt (7), <u>I</u> ssues of reproduction (4), <u>I</u> nurance (4), <u>O</u> ngoing support (1), <u>N</u> ew healthcare providers (2)  <i>Item response format</i> Patient's free response is rated as 0 = <i>inadequate</i> , 0.5 = <i>partial</i> , or 1 = <i>adequate knowledge/skill</i>  <i>Scoring</i> Subscale score = sum/# of items (range: 0-1); Total score = sum of subscale scores (range: 0-10)	<i>Internal consistency</i> Item-total correlations ( $r$ range: 0.16-0.62), item-subscale ( $r$ range: 0.42-0.85), subscale-total ( $r$ range: 0.34-0.74)  <i>Interrater reliability</i> Agreement among trained administrators (weighted $\kappa = 0.71-0.76$ )  <i>Validity</i> Content and construct validity supported by measure development process (i.e., consultation of HCT experts); Convergent (age); EFA supports 7-subscale structure reflected in Version 4
Ferris et al., 2012; STARx Program (Univ. of North Carolina – Chapel Hill <a href="http://www.med.unc.edu/transition/transition-tools">http://www.med.unc.edu/transition/transition-tools</a> )	Ages: 12-22 years Conditions: CKD/hypertension (121), diabetes mellitus (6), IBD (94), renal transplant (21), SCD (13), SLE (1)	<i>Measure refinement</i> Feedback from clinicians, patients, and HCT experts informed modification and removal of items; EFA of version 3 led to removal of additional items		
Copies of Versions 3 and 4 available on STARx Program website; Copy of Version 3 in Appendix of Ferris et al., 2012				
[Questionnaire for pre-transfer group]	N = 55	<i>Item construction</i> Modeled after questionnaires from the “On Your Own Feet Ahead” collaborative	14 patient SR items	<i>Internal consistency</i> Cronbach's $\alpha = 0.95$
van der Toorn et al., 2013	Ages: 10-38 years Condition: Complex bladder disorder		<i>Item response format</i> 4-pt and 5-pt Likert scales (1 = <i>I totally disagree</i> , 4/5 = <i>I totally agree</i> )	<i>Validity</i> Not reported
Copy of measure is not available per author's communication			<i>Scoring</i> Not reported	

<sup>2</sup> TRxANSITION Version 4 has 21 items total: Type of chronic health condition (3 items), Rx/medications (3), Adherence (2), Nutrition (2), Self-management (6), Inurance (4), Ito new healthcare providers (1)

TR Measure	Sample	Development	Characteristics	Psychometric Properties
Readiness Questionnaire Cappelli, MacDonald, & McGrath, 1989 Copy of measure and scoring protocol available in Appendix of Cappelli et al., 1989	N = 36 Ages: adolescents and young adults Condition: CF	<i>Item construction</i> Interviewed HCT experts (pediatric and adult HCPs, adult CF patients, child CF caregivers) <i>Measure refinement</i> HCT experts rated importance of potential items	24 parent SR items <i>Subscales (number of items)</i> Knowledge (15) Behavior (9) <i>Item response format</i> Free-response and multiple-choice items worth 1-2 points each <i>Scoring</i> Total = sum of item responses (range: 0-28); Knowledge = sum of subscale item responses (range: 0-13); Behavior = sum of subscale item responses (range: 0-15)	<i>Reliability</i> Not reported <i>Validity</i> Content and construct validity supported by measure development process (i.e., consultation of HCT experts); Concurrent (better agreement between total (and subscale scores) and caregiver classification of patient's ability to cope with transfer to adult care than age and caregiver classification)
Self-Care Independence Scale (SCIS) Patton, Graham, Varlotta, & Holsclaw, 2003 Request copy from Susana Patton, Ph.D. (spatton2@kumc.edu)	N = 76 parents of patients Ages (patients): 4-17 years Condition: CF	<i>Item construction</i> Modeled after Diabetes Independence Survey, CF experts' (HCPs, researchers) opinions <i>Measure refinement</i> CF HCPs rated relevance of potential items	44 parent SR items <i>Item response format</i> Forced-choice: Yes (child has attained mastery of this skill) or No <i>Scoring</i> Total = sum of Yes responses (range: 0-44), or % of prescribed behaviors that child has mastered (range: 0-100%) <i>Readability</i> 10 <sup>th</sup> grade reading level	<i>Internal consistency</i> Cronbach's $\alpha = 0.93$ <i>Test-retest reliability</i> Correlation between scores separated by 4-week period ( $r = 0.81$ ) <i>Validity</i> Concurrent (CF knowledge, negative association with dependency); Convergent (age, disease duration)



TR Measure	Sample	Development	Characteristics	Psychometric Properties
Diabetes Independence Survey (DIS), parent version	N = 490 parents of patients (Wysocki et al., 1992); N = 648 parents (Wysocki et al., 1996)	<i>Item construction</i> American Diabetes Association recommendations for mastering diabetes self-management skills informed creation of HCP survey (Wysocki, Meinhold, Cox, & Clarke, 1990)	38 parent SR items  <i>Item response format</i> Forced-choice: Yes (child has attained mastery of this skill) or No  <i>Scoring</i> Total = sum of Yes responses (range: 0-38)	<i>Internal consistency</i> Cronbach's $\alpha = 0.91$  <i>Interrater reliability</i> Correlation between mothers' and fathers' scores ( $r = 0.78$ , Wysocki et al., 1996);
Copy of measure and available in Appendix of Wysocki et al., 1992	Ages (patients): 3-18 years Condition: Diabetes (type 1)	<i>Measure refinement</i> Original HCP-report survey was modified for administration to parents	<i>Readability</i> 6 <sup>th</sup> -7 <sup>th</sup> grade reading level (parent version)	<i>Validity</i> Concurrent (direct observational test of diabetes knowledge and skills, parent-child sharing of diabetes-related responsibilities, agreement between parents' and HCPs' sequencing of skill mastery by patient age); Convergent (age, disease duration); PCA supports single construct measured by DIS
Transition Readiness Questionnaire	N = 12 patients ( $\geq 18$ years) N = 39 parents/caretakers Ages (patients): 9-25 years Condition: HIV/AIDS	<i>Item construction</i> Review of literature discussing factors identified as potential obstacles to successful HCT	21 patient (and parent) SR items  <i>Item response format</i> Forced-choice responses, item responses were rated 0-1 or 0-2 points  <i>Scoring</i> Global readiness score (sum of points) categorized as <i>Poor</i> , <i>Moderate</i> , <i>Good</i> , or <i>Excellent</i>	<i>Reliability</i> Not reported  <i>Validity</i> Scores increased over course of TR program; Concurrent (greater increase in scores for patients who identified barriers at pre-intervention); Convergent (confidence in home provider; negative associations with state anxiety and years treated at the National Institute of Health)
Crohn's and Colitis Knowledge (CCKNOW) Score	N = 354 Ages: not specified in Eaden et al., 1999; (10-20 years in Huang, Tobin, & Tompane, 2012) Condition: IBD	<i>Item construction</i> Review of educational materials in pediatric gastroenterology clinic, consultation with IBD HCPs  <i>Measure refinement</i> HCP review and EFA informed item modification and elimination	24 patient SR items  <i>Item response format</i> Multiple-choice items worth 1-point each  <i>Scoring</i> Total = sum of item scores (range: 0-24)  <i>Readability</i> Flesch Kincaid reading grade level: 4.4	<i>Internal consistency</i> Cronbach's $\alpha = 0.95$  <i>Validity</i> Concurrent (pilot testing found that junior physicians scored higher than registered nurses, who scored higher than ward clerks; patient members of The National Association of Crohn's and Colitis patient self-help group scored higher than non-members); EFA supported interpretable 5-factor structure (i.e., general IBD knowledge, medication, anatomy, disease complications, and diet)
Eaden, Abrams, & Mayberry, 1999				
Copy of measure available in Appendix 1 of Eaden et al., 1999				

TR Measure	Sample	Development	Characteristics	Psychometric Properties
MyHealth Passport for IBD Questionnaire	N = 78 patients N = 64 parents	<i>Item construction</i> Adaptation of MyHealth Passport (Good2Go Transition Program) for IBD based on expert (HCPs) opinion	19 patient (and parent) SR items  <i>Item response format</i> Free-response items and items with menu of choices  <i>Scoring</i> Participant responses compared with patient medical record to evaluate accuracy (MyHealth Passport used as educational assessment and intervention tool)	<i>Reliability</i> Not reported  <i>Validity</i> Convergent (likelihood of answering specific items correctly related to patient gender, specific diagnosis, and age)
Benchimol et al., 2011 Example of measure available in Figure 1 of Benchimol et al., 2011; Electronic version available on <a href="https://www.sickkids.ca/myhealthpassport/">https://www.sickkids.ca/myhealthpassport/</a>	Ages: 14-18 years Condition: IBD	<i>Measure refinement</i> Participant feedback informed modifications to items' wording		
Readiness for Transition Questionnaire (RTQ), teen and parent versions	N = 48 patients N = 32 parents Ages (patients): 15-21 years	<i>Item construction</i> Review of HCT literature, adolescent medicine policy statements and position papers, and existing HCT measures  <i>Measure refinement</i> Kidney transplant HCT HCPs reviewed and approved items	22 patient (and parent) SR items  <i>Subscales (number of items)</i> Overall TR (2, RTQ-Overall); Adolescent Responsibility (10, RTQ-AR); Parental Involvement (10, RTQ-PI)  <i>Item response format</i> RTQ-Overall 4-pt Likert (1 = not at all ready, 4 = completely ready); RTQ-AR 4-pt Likert (1 = not at all responsible, 4 = responsible almost all the time); RTQ-PI 4-pt Likert (1 = not at all involved, 4 = involved almost all the time)	<i>Internal consistency</i> RTQ-Overall Cronbach's $\alpha = 0.79$ (teen), 0.88 (parent); RTQ-AR Cronbach's $\alpha = 0.86$ (teen), 0.85 (parent); RTQ-PI Cronbach's $\alpha = 0.94$ (teen), 0.89 (parent)  <i>Interrater reliability</i> Correlations between teen and parent RTQ-Overall ( $r = 0.68$ ); RTQ-AR ( $r = 0.50$ ); RTQ-PI ( $r = 0.58$ )
Gilleland, Amaral, Mee, & Blount, 2012 Copy of RTQ-Teen available in Table 1 of Gilleland et al., 2012; Request copies from Jordan Gilleland, Ph.D. (jordan.gilleland@choa.org)	Condition: Kidney failure (kidney transplant recipients)		<i>Scoring</i> Subscale scores = sum of item responses; RTQ-Overall (range: 2-8), RTQ-AR (range: 10-40), RTQ-PI (range: 10-40)	<i>Validity</i> Convergent (RTQ-Overall associated with RTQ-AR, RTQ-PI (negative association), medication knowledge, adherence barriers (negative), teen-parent relationship quality)
			<i>Readability</i> 5 <sup>th</sup> grade reading level	

TR Measure	Sample	Development	Characteristics	Psychometric Properties
Developmentally Based Skills Checklist	N = 52 (Annunziato et al., 2011) N = 63 (Piering et al., 2011)	<i>Item construction</i> Adaptation of the Developmentally Based Skills Checklist (Sawin et al., 1999), which was based on the Developmentally-Based Self-Advocacy Goals for Adolescents (Miola & Vessey, 1997); convergent with Pediatric Committee of the American Society of Transplantation tasks	22 patient SR items  <i>Item response format</i> 3-pt Likert (1 = never, 3 = always)  <i>Scoring</i> Total = sum of item responses (range: 22-66); Percent Always = number of <i>always</i> responses divided by 22 items	<i>Internal consistency</i> Cronbach's $\alpha = 0.74-0.81$  <i>Validity</i> Convergent (age, age at time of transplantation x gender interaction)
Annunziato et al., 2011; Piering et al., 2011	Ages: 14-27 years Condition: Liver disease (liver transplant recipients)			
Items listed in Table 1 of Annunziato et al., 2011 or Piering et al., 2011;				
Request copy from Rachel Annunziato, Ph.D. (annunziato@fordham.edu)				
Transition Readiness Survey – Adolescent/Young Adult Version (TRS:A/YA) and Parent Report (TRS:P)	N = 71 patients N = 58 parents  Ages (patients): 11-20 years  Condition: Liver disease (liver transplant recipients)	<i>Item construction</i> Review of HCT, self-management, and medication adherence literature; clinical observations; expert opinion (consultation with pediatric liver transplant team members)	38 patient SR items, and 4 clinician administered and rated items (A/YA); 36 parent SR items (P)  <i>Subscales (number of items A/YA; P)</i> Adolescent self-management (12; 11), Adolescent perceived regimen knowledge (10; 7), Demonstrated skills (9; 5), Adolescent psychosocial adjustment (11; 11), [parent's] Regimen knowledge (2, P only)  <i>Item response format</i> 3-pt and 4-pt Likert reflecting perceived presence of knowledge/skills or agreement; Ratings of directly observed skill demonstration on 3-pt scale (1 = <33% correct, 3 = >66% correct); Ratings of free-response demonstrations of knowledge (1 = none, 3 = all)	<i>Internal consistency</i> Total score Cronbach's $\alpha = 0.85$ (A/YA), 0.75 (P)  Subscales Cronbach's $\alpha$ range: 0.68-0.82 (A/YA), 0.19-0.79 (P)  <i>Interrater reliability</i> Correlations between patients and parents' subscale scores ( $r$ range: -0.26 – 0.58)  <i>Validity</i> Convergent (all subscales except Demonstrated skills and [parent] Regimen knowledge associated with age; Self-management subscale with medication nonadherence; [parent] Regimen knowledge subscale with clinic attendance rate); CFA supported 4-factor structure for A/YA and P versions (factors corresponded to Demonstrated skills, Self-management, Psychosocial adjustment, Adolescent perceived regimen knowledge)
Fredericks et al., 2010				
Request copy from Emily Fredericks, Ph.D. (emfred@med.umich.edu)				

TR Measure	Sample	Development	Characteristics	Psychometric Properties
[adaptation of CA HRTW]	N = 52	<i>Item construction</i> Adaptation of California Healthy and Ready to Work HCT Guide (Betz, 2000)	15 patient SR items	<i>Reliability</i> Not reported
Lawson et al., 2011	Ages: 13-20 years Condition: Rheumatic disorders		<i>Item response format</i> Forced choice ( <i>completed independently, completed with some assistance, or completed by someone else</i> )	<i>Validity</i> Convergent (age)
Items listed in Table 2 of Lawson et al., 2011; Request copy from Erica Lawson, M.D. (lawson@peds.ucsf.edu)			<i>Scoring</i> Responses examined individually by item (descriptive information about % of patients able to complete particular task independently)	
How Much Do I Know About SCD	N = 44	<i>Item construction</i> Review of medical literature relevant to SCD	12 patient SR items	<i>Reliability</i> Not reported
Baskin, Collins, Kaslow, & Hsu, 2002	Ages: 12-18 years Condition: SCD		<i>Item response format</i> Multiple-choice items worth 1 point each	<i>Validity</i> Scores increased over course of psychoeducational intervention relative to TAU control group
Request copy from Monica Baskin, Ph.D. (mbaskin@sph.emory.edu)		<i>Measure refinement</i> HCPs rated items' importance	<i>Scoring</i> Total = number of correct responses (range: 0-12)	
SCD Adolescent Readiness Scale (SCDARS)	N = 224	<i>Item construction</i> Modeled after "Are You Ready to Manage Your Own Health Care Questionnaire" (Pacer Center, 1993)	35 patient SR items	<i>Internal consistency</i> SCDARS Cronbach's $\alpha = 0.88$ Subscales Cronbach's $\alpha$ range: 0.69-0.85
Anie & Telfair, 2005	Ages: 14 years and older Condition: SCD		<i>Subscales</i> Responsibility for care; Independence with care; Knowledge of SCD; Confidence with care	<i>Validity</i> Convergent (age, education level, psychological symptoms); EFA supported 4 factor structure
Request copy from Kofi Anie, Ph.D. (k.anie@imperial.ac.uk)		<i>Measure refinement</i> EFA informed formation of subscales	<i>Item response format</i> 4-pt Likert (1 = <i>never or rarely</i> , 4 = <i>always</i> )	
			<i>Scoring</i> Subscale score = mean of individual item scores (range: 1-4)	

TR Measure	Sample	Development	Characteristics	Psychometric Properties
SCD Knowledge Test (SCDKT), patient and parent versions Kaslow et al., 2000	N = 39 patients N = 39 parents Ages (patients): 7-16 years Condition: SCD	<i>Item construction</i> Focus group meetings with HCPs and family members of SCD patients <i>Measure refinement</i> Second group of HCPs and family members' review and pilot testing of measure with children and adults guided modification and elimination of items	10 patient (and parent) SR items <i>Item response format</i> Multiple-choice and free-response items worth 1 point each <i>Scoring</i> Total = number of correct responses (range: 0-10)	<i>Internal consistency</i> Cronbach's $\alpha = 0.72$ (patient), 0.73 (parent) <i>Validity</i> Scores increased over course of a family psychoeducational intervention relative to TAU control group
Copy of measure available in Appendix of Kaslow et al., 2000				
Transition Knowledge Questionnaire (TKQ) Newland, Cecil, & Fithian, 2000; Newland, 2008 Request copy from Jamesetta Newland, Ph.D. (jan7@nyu.edu)	N = 74 Ages: 13-21 years Condition: SCD	<i>Item construction</i> Literature review led to the identification of relevant content areas <i>Measure refinement</i> Internal and external experts' ratings of item relevance and clarity and also of instrument as a whole were entered into calculation of the content validity index as well as pilot testing guided modification and elimination of items	25 patient SR items <i>Item response format</i> Multiple-choice items worth 1 point each <i>Scoring</i> Total = number of correct responses (range: 0-25) <i>Readability</i> 6 <sup>th</sup> -7 <sup>th</sup> grade reading level	<i>Internal consistency</i> Cronbach's $\alpha = 0.71-0.79$ <i>Validity</i> Content validity supported by measure development process (i.e., calculation of content validity index based on HCT experts' review); Convergent (age, negative association with independence)

*Notes.* ADHD = Attention-deficit/hyperactivity disorder, ASD = Autism spectrum disorder; CF = Cystic fibrosis, CFA = Confirmatory factor analysis, CKD = Chronic kidney disease, CP = Cerebral palsy, EFA = Exploratory factor analysis, HCP = Healthcare provider, HCT = Healthcare transition, HIV/AIDS = Human immunodeficiency virus infection/Acquired immunodeficiency syndrome, IBD = Inflammatory bowel disease, MR = Mental retardation, N/A = Not applicable, PCA = Principal components analysis, SB = Spina bifida, SCD = Sickle cell disease, SHCN = Special health care needs, SLE = Systemic lupus erythematosus, SR = Self-report, TAU = Treatment as usual, TR = Transition readiness



	Adherence	Clinic attendance	Health literacy	Condition/tx knowledge	Health behaviors <sup>a</sup>	Avoids high-risk behaviors <sup>b</sup>	Obtains/keeps medical records	Has emergency plan	Assumes responsibility	Communicates needs to HCPs	Advocates for services	Organizes resources/services <sup>c</sup>	Aware of rights/protections	Health insurance knowledge	Basic anatomy knowledge	General Independence	Perception of transition	Other
Developmentally Based Skills Checklist	•			•	•	•	•		•	•		•		•				•
TRS			•	•					•									•
[adaptation of CA HRTW] Rheumatic disorders	•			•	•	•	•	•	•	•				•				•
How Much Do I Know About SCD				•														
SCDARS				•					•							•		•
SCDKT				•														
TKQ		•		•											•			•

Notes. CA HRTW = California Health and Ready to Work transition health care assessment tool, CCKNOW = Crohn's and Colitis Knowledge score, CF = Cystic fibrosis, DIS = Diabetes Independence Survey, HCP = Health care provider, HIV/AIDS = Human immunodeficiency virus infection/Acquired immunodeficiency syndrome, IBD = Inflammatory bowel disease, ON TRAC = Am I ON TRAC for Adult Care Questionnaire, REALM-Teen = Rapid Estimate of Adolescent Literacy in Medicine, RTQ = Readiness for Transition Questionnaire, SCD = Sickle cell disease, SCDARS = SCD Adolescent Readiness Scale, SCDKT = SCD Knowledge Test, SCIS = Self-Care Independence Scale, TKQ = Transition Knowledge Questionnaire, TRAQ = Transition Readiness Assessment Questionnaire, TRS = Transition Readiness Survey, Tx = Treatment.

<sup>a</sup>Health behaviors (e.g., exercise, nutrition, sleep)

<sup>b</sup>High-risk behaviors (e.g., smoking, drinking, use of illicit drugs, sexually transmitted infections and unwanted pregnancy)

<sup>c</sup>Ability to organize resources/services to meet health-related needs (e.g., transportation, interpreter, planning to take care of health needs, making appointments, filling prescriptions)

Table 3. Study Sample Socio-Demographic Characteristics

	All Clinics n = 152	S&T n = 66	MN n = 7	SD n = 44	EDICS n = 6	RTC n = 3	S&T/ EDICS n = 26
<b>Gender</b>							
% Female	57.2%	59.1%	28.6%	59.1%	50.0%	100.0%	53.8%
<b>Age at last Transition Clinic Appointment (years)</b>							
<i>M (SD)</i>	19.6 (1.68)	20.1 (1.84)	18.4 (0.95)	18.6 (0.80)	18.7 (0.97)	18.6 (1.02)	20.5 (1.7)
Min.-Max.	17.1-25.3	17.1-25.3	17.6-20.2	17.3-20.2	17.7-20.5	17.9-19.7	17.5-23.9
<b>Race/Ethnicity</b>							
% Non-Hispanic White	77.6%	78.8%	100.0%	79.5%	66.7%	33.3%	73.1%
% Non-Hispanic Black	9.2%	6.1%	0.0%	11.4%	16.7%	0.0%	15.4%
% Hispanic or Latino/Latina	7.2%	9.1%	0.0%	4.5%	0.0%	33.3%	7.7%
% Asian	1.3%	0.0%	0.0%	2.3%	0.0%	0.0%	3.8%
% American Indian or Alaska Native	0.7%	0.0%	0.0%	2.3%	0.0%	0.0%	0.0%
% Biracial or Multiracial	1.3%	0.0%	0.0%	0.0%	16.7%	33.3%	0.0%
% Other or Unknown	2.7%	6.0%	0.0%	0.0%	0.0%	0.0%	0.0%
<b>Preferred Language</b>							
English	96.1%	95.5%	100.0%	100.0%	100.0%	100.0%	88.5%
Non-English but no interpreter needed	3.9%	4.5%	0.0%	0.0%	0.0%	0.0%	11.5%
<b>Educational Level at last Transition Clinic Appointment</b>							
Dropped out of High School	0.007%	1.5%	0.0%	0.0%	0.0%	0.0%	0.0%
Attending High School	25.0%	13.6%	71.4%	43.2%	33.3%	66.7%	3.8%
Graduated High School or Passed GED	24.3%	21.2%	14.3%	27.3%	16.7%	0.0%	34.6%
Dropped out of Post-Secondary Program	2.6%	4.5%	0.0%	2.3%	0.0%	0.0%	0.0%
Attending Post-Secondary Program	41.4%	48.5%	14.3%	27.3%	50.0%	33.3%	53.8%
Graduated from Post-Secondary Program	5.3%	9.1%	0.0%	0.0%	0.0%	0.0%	7.7%
Unknown	0.7%	1.5%	0.0%	0.0%	0.0%	0.0%	0.0%
<b>Employment Status at last Transition Clinic Appointment</b>							
Not Employed	69.1%	62.1%	85.7%	79.5%	66.7%	66.7%	65.4%
Employed Part-Time	11.8%	12.1%	14.3%	11.4%	33.3%	33.3%	11.5%
Employed Full-Time	19.1%	25.8%	0.0%	9.1%	0.0%	0.0%	23.1%
<b>Insurance Status at last Transition Clinic Appointment</b>							
Private Insurance	69.7%	69.7%	42.9%	65.9%	83.3%	66.7%	80.8%
Public Insurance	23.0%	16.7%	57.1%	31.8%	16.7%	33.3%	15.4%
Self-Pay	7.2%	13.6%	0.0%	2.3%	0.0%	0.0%	3.8%
Receiving CMH Financial Aid	7.9%	9.1%	0.0%	4.5%	16.7%	0.0%	11.5%
<b>Distance between Residence and CMH (miles)</b>							
<i>M (SD) [Mdn]<sup>a</sup></i>	48.8 (50.4)	44.8 (49.2)	43.5 (29.6)	51.7 (49.5)	22.8 (27.6) [14.8]	35.7 (35.7)	60.3 (63.0)
Min.-Max.	1.8-224	4.8-205.0	10.3-83.7	2.5-196.0	1.8-76.6	10.9-76.6	1.8-224.0
<b>Adults with a Legal Guardian</b>							
Patients 18 years or older (n)	129	61	3	33	5	2	25
% with a Legal Guardian	7.0%	3.3%	0.0%	15.2%	0.0%	0.0%	8.0%

Notes: Children's Mercy Hospital Transition Clinic Abbreviations: S&T = Survive and Thrive Clinic, MN = Muscle Nerve Clinic, SD = Spinal Defects Clinic, EDICS = Endocrine Disorders in Cancer Survivors, RTC = Rheumatology Transition Clinic, S&T/EDICS = patients seen in both the S&T and EDICS clinics; *M* = mean, *SD* = standard deviation, *Mdn* = median, Min. = minimum, Max. = maximum;

<sup>a</sup>The *Mdn* was reported to estimate central tendency when values were not normally distributed for a variable.



Table 4. Study Sample Medical Characteristics

	All Clinics n = 152	S&T n = 66	MN n = 7	SD n = 44	EDICS n = 6	RTC n = 3	S&T/ EDICS n = 26
<b>Age at Diagnosis of Primary Chronic Condition (years)</b>							
<i>M (SD) [Mdn]<sup>a</sup></i>	6.3 (6.1)	8.0 (5.5)	3.1 (4.0)	0.8 (3.1) [0.0]	13.1 (5.4) [15.2]	16.8 (0.6)	9.3 (4.8)
Min.-Max.	0.0-19.6	0.5-19.6	0.0-9.7	0.0-13.7	2.3-16.6	16.3-17.4	0.7-17.2
<b>Duration of Primary Chronic Condition (i.e., years between diagnosis and last transition clinic appointment)</b>							
<i>M (SD) [Mdn]<sup>a</sup></i>	13.3 (5.7)	12.1 (5.3)	15.3 (4.3)	17.8 (3.2) [18.6]	5.6 (5.6) [4.0]	1.7 (1.5)	11.1 (4.6)
Min.-Max.	0.7-21.8	1.3-21.8	7.9-19.0	4.9-20.2	1.1-16.6	0.7-3.4	3.8-20.0
<b>Number of Secondary Chronic Medical Conditions</b>							
<i>M (SD) [Mdn]<sup>a</sup></i>	3.2 (2.6)	1.8 (1.9) [2.0]	4.4 (1.9)	4.3 (2.1)	2.7 (2.3) [2.0]	1.0 (1.7)	5.1 (3.4)
Min.-Max.	0-13	0-8	1-7	1-11	1-7	0-3	0-13
<b>Patients having 1 or more Neurocognitive or Neurodevelopmental Disorders</b>							
%	35.5%	27.3%	28.6%	45.5%	33.3%	33.3%	42.3%
<b>Patients having Psychiatric Disorders</b>							
% having 0 psychiatric disorder	77.6%	72.7%	100.0%	81.8%	66.7%	100.0%	76.9%
% having 1 psychiatric disorder	18.4%	25.8%	0.0%	11.4%	16.7%	0.0%	19.2%
% having ≥2 psychiatric disorders	4.0%	1.5%	0.0%	6.8%	16.7%	0.0%	3.8%
<b>Patients with a History of Major Surgical Procedure(s)</b>							
%	71.8%	45.5%	71.4%	97.7%	100.0%	0.0%	96.2%
<b>Number of Pediatric Medical Specialties involved in Patient's Care</b>							
<i>M (SD)</i>	4.9 (3.2)	2.6 (1.6)	7.4 (3.3)	7.9 (2.9)	5.7 (0.8)	3.3 (2.3)	5.1 (2.2)
Min.-Max.	1-15	1-8	4-13	3-15	5-7	2-6	2-10
<b>Number of Outpatient Medications at last Transition Clinic Appointment</b>							
<i>M (SD) [Mdn]<sup>a</sup></i>	2.8 (3.3) [2.0]	1.7 (2.2) [1.0]	5.1 (6.8)	4.1 (4.0) [3.0]	3.5 (3.3) [2.0]	4.7 (4.0)	3.0 (2.1)
Min.-Max.	0-22	0-10	0-18	0-22	1-10	1-9	0-8
<b>Number of Outpatient Medications and Supplements at last Transition Clinic Appointment</b>							
<i>M (SD) [Mdn]<sup>a</sup></i>	3.6 (3.8) [2.5]	2.1 (2.5) [1.0]	6.7 (7.0)	4.6 (4.5) [4.0]	5.3 (3.3)	6.3 (5.0)	4.0 (2.7)
Min.-Max.	0-25	0-13	1-19	0-25	2-11	1-11	0-9
<b>Medical Regimen Complexity Index</b>							
<i>M (SD) [Mdn]<sup>a</sup></i>	9.2 (11.3) [6.0]	4.7 (6.0) [3.0]	21.9 (27.9)	11.9 (12.4) [9.2]	16.2 (12.8)	13.5 (11.5)	10.3 (8.0)
Min.-Max.	0.0-73.5	0.0-29.0	2.0-73.5	0.0-62.5	4.0-37.5	2.0-25.0	0.0-30.5
<b>Patients having the following Components in their Outpatient Treatment Regimen at last Transition Clinic Appointment</b>							
% having Medications or Supplements	82.9%	68.2%	100.0%	90.9%	100.0%	100.0%	96.2%
% having Physical Exercises	40.1%	30.3%	85.7%	56.8%	33.3%	66.7%	23.1%
% having Dietary Recommendations	44.7%	53.0%	42.9%	29.5%	50.0%	66.7%	46.2%
% having Self-Monitoring Recommendations	0.7%	0.0%	0.0%	0.0%	0.0%	0.0%	3.8%
% having Other Regimen Components	31.6%	0.0%	71.4%	93.2%	0.0%	66.7%	0.0%

Notes: Children's Mercy Hospital Transition Clinic Abbreviations: S&T = Survive and Thrive Clinic, MN = Muscle Nerve Clinic, SD = Spinal Defects Clinic, EDICS = Endocrine Disorders in Cancer Survivors, RTC = Rheumatology Transition Clinic, S&T/EDICS = patients seen in both the S&T and EDICS clinics; M = mean, SD = standard deviation, Mdn = median, Min. = minimum, Max. = maximum;

<sup>a</sup>The Mdn was reported to estimate central tendency when values were not normally distributed for a variable.

Table 5. Study Sample Pediatric and Transition Services Engagement

	All Clinics n = 152	S&T n = 66	MN n = 7	SD n = 44	EDICS n = 6	RTC n = 3	S&T/EDICS n = 26
<b>Number of Transition Preparation Appointments Attended</b>							
<i>M (SD)</i>	3.0 (1.5)	2.4 (1.2)	3.4 (2.4)	3.4 (1.1)	1.7 (0.8)	1.3 (0.6)	4.0 (1.6)
Min.-Max.	1-8	1-5	1-8	2-6	1-3	1-2	2-8
<b>Percentage of CMH Transition Clinic Appointments Attended</b>							
<i>M (SD)</i>	95.7% (11.5%)	96.7% (11.6%)	95.6% (8.0%)	93.7% (10.9%)	84.7% (27.1%)	100.0% (0.0%)	98.6% (5.3%)
[ <i>Mdn</i> ] <sup>a</sup>	[100.0%]	[100.0%]	[100.0%]	[100.0%]	[100.0%]	[100.0%]	[100.0%]
Min.-Max.	33.3%-100.0%	33.3%-100.0%	80.0%-100.0%	66.7%-100.0%	33.3%-100.0%	100.0%-100.0%	75.0%-100.0%
<b>Percentage of CMH Outpatient Appointments Attended</b>							
<i>M (SD)</i>	83.3% (11.1%)	83.4% (11.9%)	83.1% (10.9%)	83.2% (12.4%)	78.3% (3.9%)	81.0% (8.4%)	84.3% (8.3%)
Min.-Max.	47.1%-100.0%	58.3%-100.0%	68.0%-100.0%	47.1%-100.0%	72.2%-82.1%	73.3%-90.0%	67.0%-100.0%

Note: Children's Mercy Hospital Transition Clinic Abbreviations: S&T = Survive and Thrive Clinic, MN = Muscle Nerve Clinic, SD = Spinal Defects Clinic, EDICS = Endocrine Disorders in Cancer Survivors, RTC = Rheumatology Transition Clinic, S&T/EDICS = patients seen in both the S&T and EDICS clinics; *M* = mean, *SD* = standard deviation, *Mdn* = median, Min. = minimum, Max. = maximum.

<sup>a</sup> The *Mdn* was reported to estimate central tendency when values were not normally distributed for a variable.

Table 6. Transitioning Preparedness Survey Scores from Last Administration

<i>TPS 18+ Version</i>							
	All Clinics	S&T	MN	SD	EDICS	RTC	S&T/EDICS
	n = 110	n = 53	n = 4	n = 29	n = 3	n = 2	n = 19
TPS Total Score							
<i>M (SD)</i>	77.5% (20.6%)	81.6% (19.2%)	73.5% (7.6%)	73.4% (21.6%)	88.2% (10.2%)	67.6% (20.8%)	72.4% (24.1%)
Min.-Max.	17.6%-100.0%	23.3%-100.0%	64.7%-82.4%	35.3%-100.0%	82.4%-100.0%	52.9%-82.4%	17.6%-100.0%
Pooled <i>M</i> <sup>a</sup>	78.9%	83.2%	73.7%	74.5%	88.2%	67.6%	74.3%
Knowledge Subscale							
<i>M (SD)</i>	76.8% (25.4%)	77.4% (25.7%)	85.7% (20.2%)	75.9% (27.3%)	85.7% (24.7%)	71.4% (0.0%)	73.7% (25.8%)
Min.-Max.	0.0%-100.0%	0.0%-100.0%	57.1%-100.0%	14.3%-100.0%	57.1%-100.0%	71.4%-71.4%	14.3%-100.0%
Pooled <i>M</i> <sup>a</sup>	78.3%	79.4%	85.7%	77.1%	85.7%	71.4%	75.2%
Skill Subscale							
<i>M (SD)</i>	73.8% (26.9%)	83.6% (20.3%)	58.3% (9.6%)	61.5% (30.9%)	88.9% (19.2%)	58.3% (35.4%)	67.5% (29.6%)
Min.-Max.	0.0-100.0%	33.3%-100.0%	50.0%-66.7%	0.0%-100.0%	66.7%-100.0%	33.3%-83.3%	0.0%-100.0%
Pooled <i>M</i> <sup>a</sup>	75.2%	85.1%	58.8%	62.6%	88.9%	58.3%	69.8%
Taking Charge Subscale							
<i>M (SD) [Mdn]</i> <sup>b</sup>	85.1% (23.1%)	87.5% (23.5%) [100.0%]	75.0% (20.4%)	87.1% (21.8%)	91.7% (14.4%)	75.0% (35.4%)	77.6% (24.9%)
Min.-Max.	0.0%-100.0%	0.0%-100.0%	50.0%-100.0%	25.0%-100.0%	75.0%-100.0%	50.0%-100.0%	25.0%-100.0%
Pooled <i>M</i> <sup>a</sup>	85.4%	87.1%	75.0%	87.6%	91.7%	75.0%	79.3%
<i>TPS 15-17 Version</i>							
	All Clinics	S&T	MN	SD	EDICS	RTC	S&T/EDICS
	n = 42	n = 13	n = 3	n = 15	n = 3	n = 1	n = 7
TPS Total Score							
<i>M (SD)</i>	68.0% (24.0%)	66.7% (27.7%)	72.2% (28.9%)	62.6% (18.4%)	81.5% (11.6%)	94.4% (--)	70.6% (31.7%)
Min.-Max.	11.1%-100.0%	16.7%-100.0%	38.9%-88.9%	27.8%-88.9%	72.2%-94.4%	(--)	11.1%-100.0%
Pooled <i>M</i> <sup>a</sup>	69.9%	71.5%	72.2%	62.8%	83.3%	94.4%	72.2%
Knowledge Subscale							
<i>M (SD)</i>	71.0% (32.7%)	74.4% (33.8%)	61.1% (38.5%)	62.2% (27.8%)	100.0% (0.0%)	100.0% (--)	71.4% (43.8%)
Min.-Max.	0.0%-100.0%	0.0%-100.0%	16.7%-83.3%	16.7%-100.0%	100.0%-100.0%	(--)	0.0%-100.0%
Pooled <i>M</i> <sup>a</sup>	71.7%	75.8%	61.1%	62.6%	100.0%	100.0%	72.1%
Skill Subscale							
<i>M (SD)</i>	61.3% (27.7%)	56.7% (32.1%)	70.8% (40.2%)	54.2% (20.4%)	75.0% (25.0%)	87.5% (--)	71.4% (30.4%)
Min.-Max.	12.5%-100.0%	12.5%-100.0%	25.0%-100.0%	12.5%-75.0%	50.0%-100.0%	(--)	12.5%-100.0%
Pooled <i>M</i> <sup>a</sup>	64.7%	65.5%	70.8%	54.3%	77.9%	87.5%	73.7%
Taking Charge Subscale							
<i>M (SD)</i>	76.8% (25.5%)	75.0% (28.9%)	91.7% (14.4%)	80.0% (25.4%)	66.7% (14.4%)	100.0% (--)	67.9% (27.8%)
Min.-Max.	25.0%-100.0%	25.0%-100.0%	75.0%-100.0%	25.0%-100.0%	50.0%-75.0%	(--)	25.0%-100.0%
Pooled <i>M</i> <sup>a</sup>	77.8%	76.8%	91.7%	80.0%	69.2%	100.0%	69.5%

Note: Children's Mercy Hospital Transition Clinic Abbreviations: S&T = Survive and Thrive Clinic, MN = Muscle Nerve Clinic, SD = Spinal Defects Clinic, EDICS = Endocrine Disorders in Cancer Survivors, RTC = Rheumatology Transition Clinic, S&T/EDICS = patients seen in both the S&T and EDICS clinics; *M* = mean, *SD* = standard deviation, *Mdn* = median, Min. = minimum, Max. = maximum.

<sup>a</sup>TPS *M*, *SD*, and Min.-Max. values were calculated from the original dataset, which included missing values. Pooled *M* estimates were calculated using multiple imputations of the original dataset to manage missing values.

<sup>b</sup>The *Mdn* was reported to estimate central tendency when values were not normally distributed for a variable.

Table 7. Descriptive Statistics Summarizing Survey Completers' Characteristics

		Survey Completers n = 9
<b><i>SOCIO-DEMOGRAPHIC CHARACTERISTICS:</i></b>		
<b>Gender (% Female)</b>		88.9%
<b>CMH Transition Clinic Attended</b>		
	% Attended S&T	77.8%
	% Attended S&T/EDICS	22.2%
<b>Age at last Transition Clinic Appointment (years)</b>		
	<i>M (SD)</i>	21.7 (1.2)
	Min.-Max.	19.5-23.4
<b>Race/Ethnicity</b>		
	% Non-Hispanic White	77.8%
<b>Preferred Language</b>		
	English	88.9%
	Non-English but no interpreter needed	11.1%
<b>Educational Level at last Transition Clinic Appointment</b>		
	Attending Post-Secondary Program	66.7%
	Graduated from Post-Secondary Program	33.3%
<b>Employment Status at last Transition Clinic Appointment</b>		
	Not Employed	55.6%
	Employed Part-Time	44.4%
<b>Insurance Status at last Transition Clinic Appointment</b>		
	Private Insurance	88.9%
	Public Insurance	0.0%
	Self-Pay	11.1%
	Receiving CMH Financial Aid	11.1%
<b>Distance between Residence and CMH (miles)</b>		
	<i>M (SD)</i>	56.8 (55.0)
	Min.-Max.	9.7-155.0
<b>Patients 18 years and older having a Legal Guardian</b>		0.0%
<b><i>MEDICAL CHARACTERISTICS:</i></b>		
<b>Age at Diagnosis of Primary Chronic Condition (years)</b>		
	<i>M (SD)</i>	8.0 (5.1)
	Min.-Max.	0.5-17.1
<b>Duration of Primary Chronic Condition</b>		
	<i>M (SD)</i>	13.7 (4.9)
	Min.-Max.	6.2-21.8
<b>Number of Secondary Chronic Medical Conditions</b>		
	<i>M (SD)</i>	3.8 (3.2)
	Min.-Max.	0-9
<b>Patients having 1 or more Neurocognitive or Neurodevelopmental Disorders</b>		
	%	44.4%

**Patients having Psychiatric Disorders**

% having 0 psychiatric disorder	77.8%
% having 1 psychiatric disorder	22.2%

**Patients with a History of Major Surgical Procedure(s)**

%	88.9%
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**Number of Pediatric Medical Specialties involved in Patient's Care**

<i>M (SD)</i>	3.1 (1.7)
Min.-Max.	1-6

**Number of Outpatient Medications and Supplements at last Transition Clinic Appointment**

<i>M (SD)</i>	2.9 (2.0)
Min.-Max.	0-6

**Medical Regimen Complexity Index**

<i>M (SD)</i>	6.7 (4.9)
Min.-Max.	0.0-14.0

**Number of Outpatient Medical Regimen Component Types<sup>a</sup>**

<i>M (SD)</i>	1.6 (0.9)
Min.-Max.	0-3

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***PEDIATRIC AND TRANSITION SERVICES ENGAGEMENT:***

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**Number of Transition Preparation Appointments Attended**

<i>M (SD)</i>	2.9 (1.4)
Min.-Max.	1-5

**Percentage of CMH Transition Clinic Appointments Attended**

<i>M (SD) [Mdn]<sup>b</sup></i>	94.1% (12.2%) [100.0%]
Min.-Max.	66.7%-100.0%

**Percentage of CMH Outpatient Appointments Attended**

<i>M (SD)</i>	78.8% (14.0%)
Min.-Max.	58.3%-95.4%

**Transitioning Preparedness Survey (TPS) Scores from Last Administration**

Total Score	89.5% (7.7%)
Knowledge Subscale	84.1% (15.1%)
Skill Subscale	98.1% (5.6%)
Taking Charge Subscale	86.1% (18.2%)

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*Notes:* CMH = Children's Mercy Hospital; S&T = Survive and Thrive Clinic, S&T/EDICS = Survive and Thrive/Endocrine Disorders in Cancer Survivors joint clinic; *M* = mean, *SD* = standard deviation, *Mdn* = median, Min. = minimum, Max. = maximum;

<sup>a</sup>Outpatient medical regimen component types included medications/supplements, physical exercises, dietary recommendations, self-monitoring recommendations, and other regimen components.

<sup>b</sup>The *Mdn* was reported to estimate central tendency when values were not normally distributed for a variable.

Table 8. Intercorrelations between Transitioning Preparedness Survey Subscales

<i>TPS 18+ Version (n = 110)</i>			
	<b>1</b>	<b>2</b>	<b>3</b>
<b>1</b> Knowledge	--		
<b>2</b> Skill	0.593**	--	
<b>3</b> Taking Charge	0.226*	0.360**	--

<i>TPS 15-17 Version (n = 42)</i>			
	<b>1</b>	<b>2</b>	<b>3</b>
<b>1</b> Knowledge	--		
<b>2</b> Skill	0.775**	--	
<b>3</b> Taking Charge	0.262	0.262	--

Notes: \*  $p < 0.05$ , \*\*  $p < 0.01$ ; correlations are pooled estimates based on multiply imputed datasets to address missing data

Table 9. Correlations between Transitioning Preparedness Survey Scores and Transition Readiness Factors

<i>TPS 18+ Version (n = 110)</i>				
	<b>TPS Total</b>	<b>Knowledge</b>	<b>Skill</b>	<b>Taking Charge</b>
<b>Age at TPS Administration</b>	0.213*	0.137	0.274**	0.054
<b>Number of Transition Clinic Appointments Attended</b>	-0.058	0.121	-0.144	-0.203*
<b>Percentage of Transition Clinic Appointments Attended</b>	-0.155	-0.204*	-0.056	-0.084
<b>Percentage of Outpatient Pediatric Appointments Attended</b>	0.170	0.166	0.148	0.055
<b>Number of Appointments when Transition was Discussed</b>	-0.054	0.132	-0.163	-0.178

<i>TPS 15-17 Version (n = 42)</i>				
	<b>TPS Total</b>	<b>Knowledge</b>	<b>Skill</b>	<b>Taking Charge</b>
<b>Age at TPS Administration</b>	0.023	-0.028	0.096	-0.049
<b>Number of Transition Clinic Appointments Attended</b>	0.066	0.117	-0.005	0.058
<b>Percentage of Transition Clinic Appointments Attended</b>	0.039	-0.039	0.053	0.13
<b>Percentage of Pediatric Outpatient Appointments Attended</b>	0.106	-0.038	0.116	0.278
<b>Number of Appointments when Transition was Discussed</b>	0.102	0.135	0.031	0.101

*Note:* \*  $p < 0.05$ , \*\*  $p < 0.01$ ; TPS = Transitioning Preparedness Survey; correlations are pooled estimates based on multiply imputed datasets to address missing data.

Table 10. Comparison of Transitioning Preparedness Survey Scores between Patients at Lower and Higher Risk for Neurocognitive Difficulties

<i>TPS 18+ Version</i>																		
n	TPS Total			Knowledge Subscale			Skill Subscale			Taking Charge Subscale								
	Pooled M	SE	Pooled t	Pooled M	SE	Pooled t	Pooled M	SE	Pooled t	Pooled M	SE	Pooled t						
<b>Cancer or cancer treatment affected CNS*</b>																		
No	63	80.5%	2.5%	0.754	0.23	0.23	78.0%	3.2%	0.223	0.41	78.9%	3.3%	0.769	0.22	87.4%	2.9%	1.052	0.15
Yes	23	76.8%	4.7%				76.6%	6.0%			73.9%	5.2%			81.4%	4.8%		
<b>Neurocognitive or Neurodevelopmental Disorder</b>																		
No	71	83.6%	2.1%	3.296	<0.01		83.6%	2.7%	2.881	<0.01	81.1%	2.9%	3.327	<0.01	87.2%	2.6%	1.072	0.14
Yes	39	70.3%	3.5%				68.6%	4.5%			64.3%	4.3%			82.0%	4.1%		
<b>Legal Guardian for Patients 18 and older~</b>																		
No	100	81.9%	1.7%	6.063	<0.01		82.0%	2.2%	5.365	<0.01	78.5%	2.4%	4.385	<0.01	86.8%	2.2%	3.180	<0.01
Yes	6	38.2%	5.2%				31.7%	11.1%			33.9%	8.4%			56.0%	11.8%		
<i>TPS 15-17 Version</i>																		
n	TPS Total			Knowledge Subscale			Skill Subscale			Taking Charge Subscale								
	Pooled M	SE	Pooled t	Pooled M	SE	Pooled t	Pooled M	SE	Pooled t	Pooled M	SE	Pooled t						
<b>Cancer or cancer treatment affected CNS*</b>																		
No	23	62.7%	5.3%	-4.132	>0.99		64.8%	7.5%	-4.273	>0.99	57.4%	5.8%	-2.656	>0.99	70.0%	5.8%	-1.142	0.87
Yes	7	89.9%	3.9%				98.3%	2.3%			87.0%	7.0%			83.2%	7.0%		
<b>Neurocognitive or Neurodevelopmental Disorder</b>																		
No	27	75.4%	4.1%	2.098	0.02		79.0%	5.7%	1.987	0.02	70.9%	4.7%	2.142	0.02	79.0%	5.1%	0.383	0.35
Yes	15	60.1%	6.5%				58.7%	9.1%			53.4%	7.2%			75.8%	6.2%		

Notes: TPS = Transitioning Preparedness Survey; CNS = central nervous system; Pooled M = mean score pooled from multiply imputed dataset to address missing data, SE = standard error, Pooled t = independent t score pooled from multiply imputed dataset to address missing data, p = probability value, one-tailed.

\*Only cancer survivors were included in this comparison.

~4 cases were excluded from this comparison as they were younger than 18-years-old and had been administered the TPS 18+ Version.



Table 11. Survey Completers' Healthcare Transition Outcomes and Satisfaction Ratings

		<b>Survey Completers</b>
		n = 9
<b>Age at Time of Survey Completion (years)</b>		
	<i>M (SD)</i>	24.2 (1.3)
	Min.-Max.	22.5-26.6
<b>Outcome of Transition to Adult Primary Care</b>		
	% Successful	55.6%
	% Partially Successful	33.3%
	% Unsuccessful	11.1%
<b>Outcome of Transition to Adult Specialty Care</b>		
	n	7
	% Successful	42.9%
	% Partially Successful	57.1%
	% Unsuccessful	0.0%
<b>Patient Satisfaction with Transition Process</b>		
	% Entirely Satisfied	22.2%
	% Moderately Satisfied	66.7%
	% Mildly Satisfied	11.1%

Figure 1. Flow Diagram of Article Selection in Independent Systematic Review of TR Measures

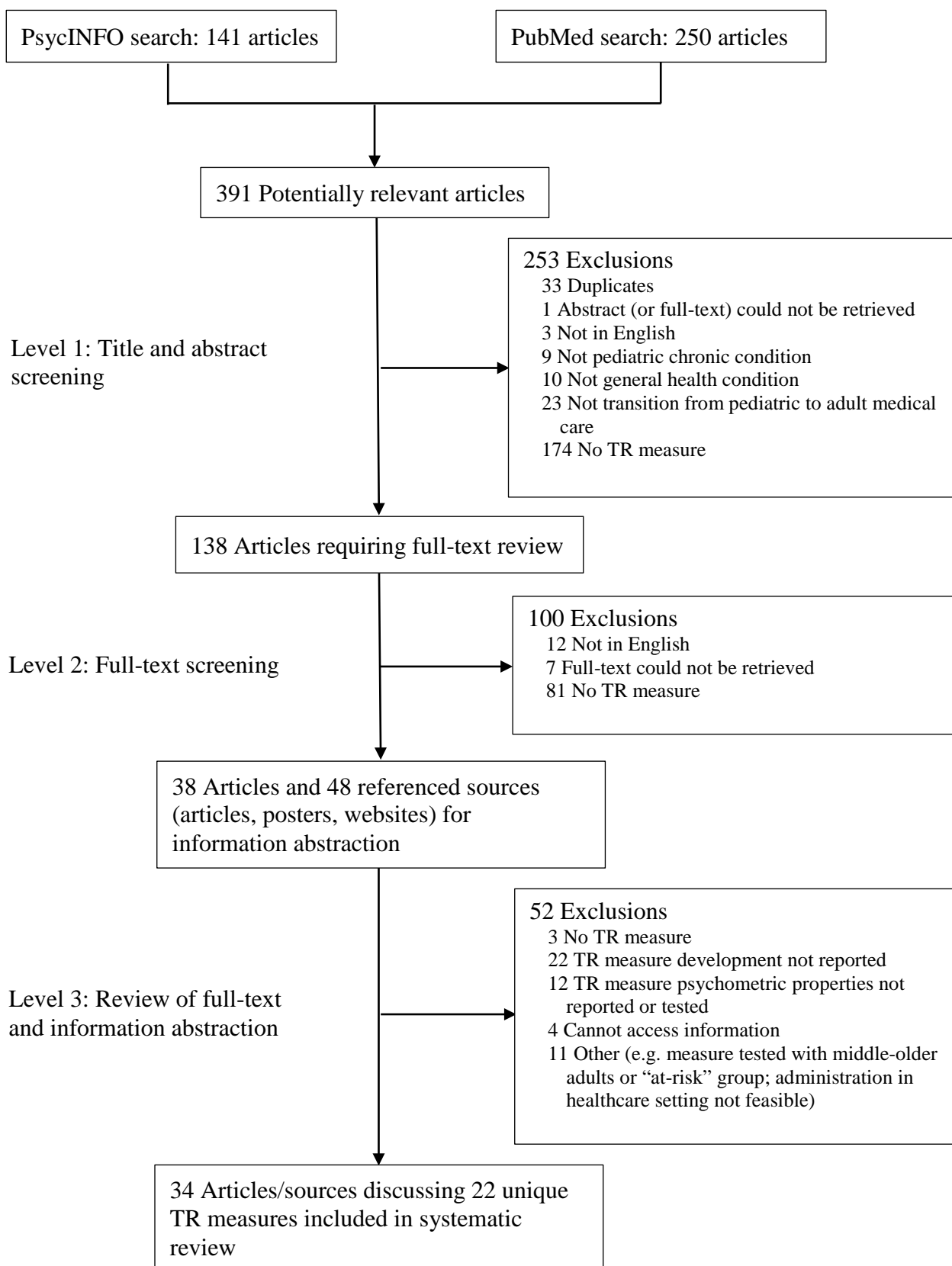
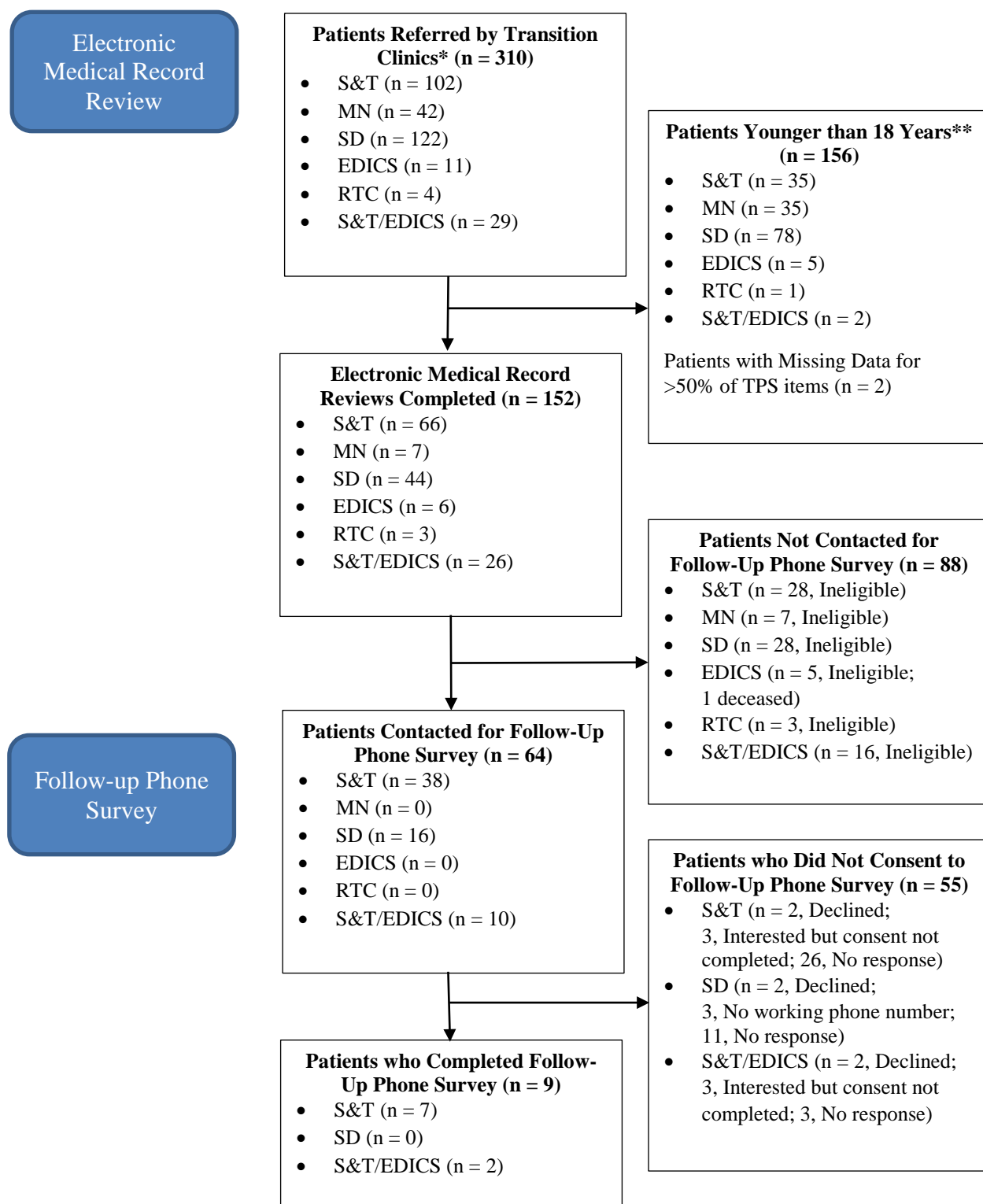


Figure 2. Consolidated Standards of Reporting Trials (CONSORT) Diagram.



Notes: S&T = Survive and Thrive Clinic, MN = Muscle Nerve Clinic, SD = Spinal Defects Clinic, EDICS = Endocrine Disorders in Cancer Survivors Clinic, RTC = Rheumatology Transition Clinic, S&T/EDICS = patients seen in both the S&T and EDICS clinics

\*Patients were referred for the Electronic Medical Record review portion of the study if they completed a Transitioning Preparedness Survey before 1/1/2015.

\*\*Patients younger than 18 years on 1/1/2015 were unlikely to have transitioned out of pediatric care at the time of data collection for this study. Data for these patients will be conducted in an extended phase of this study.

## Appendix A. Data Abstraction Protocol for Medical Chart Review

### Patient Socio-demographic Information

1. Record patient gender (code):
  - a. Male (0)
  - b. Female (1)
  - c. Female to male transgender (2)
  - d. Male to female transgender (3)
  - e. Other (4)
2. Record patient age (years and months) at the time of the most recent appointment at CMH.
3. Record patient race/ethnicity (code):
  - a. Non-Hispanic White (0)
  - b. Non-Hispanic Black (1)
  - c. Hispanic or Latino (2)
  - d. Asian (3)
  - e. American Indian or Alaska Native (4)
  - f. Native Hawaiian or Other Pacific Islander (5)
  - g. Bi-racial or Multiracial (6)
  - h. Other (7)
4. Patient's preferred language (code):
  - a. English (0)
  - b. Non-English language but the patient does not require an interpreter (1)
  - c. Non-English language and the patient requires an interpreter (2)
5. Record patient's attained educational level at the time of the most recent appointment at CMH:
  - a. Below 6<sup>th</sup> grade (0)
  - b. 6<sup>th</sup>-8<sup>th</sup> grade (1)
  - c. Dropped out of high school (2)
  - d. 9<sup>th</sup>-12<sup>th</sup> grade, attending high school (3)
  - e. Graduated high school or passed General Educational Development tests without pursuing higher education (4)
  - f. Dropped out of post-secondary educational program (5)
  - g. Attending post-secondary educational program (6)
  - h. Graduated from a post-secondary educational program (7)
6. Record the patient's employment status at the time of the most recent appointment at CMH (code):
  - a. Not employed (0)
  - b. Employed part-time (1)
  - c. Employed full-time (2)
7. Record the patient's county and state of residence at the time of the most recent appointment at CMH.
  - a. Also calculate distance from patient's county of residence to CMH (in miles).
8. Record insurance type/status (code):
  - a. Private insurance (0)
  - b. Public insurance (e.g., Medicaid) (1)

- c. Uninsured (2)
- 9. Record whether or not the patient qualifies for CMH financial aid (code):
  - a. No, the patient does not qualify for financial aid (0)
  - b. Yes, the patient qualifies for financial aid and receives aid (1)
  - c. The patient qualifies for financial aid but does not use it (2)
- 10. For patients over 18 years, record whether or not the patient has a legal guardian.
  - a. No (0)
  - b. Yes (1)
  - c. Guardianship in process (2)

#### Patient Medical Characteristics

1. Record the CMH clinic through which the patient primarily received care:
  - a. Survive and Thrive (1)
  - b. Muscle Nerve (2)
  - c. Spinal Defects (3)
  - d. Endocrine Disorders in Cancer Survivors (EDICS) (4)
  - e. Rheumatology (5)
  - f. Survive and Thrive and EDICS (6)
2. Record the specific diagnosis of the patient's primary chronic, pediatric-onset medical condition.
  - a. For cancer survivors, record specific primary cancer diagnosis.
    - i. Note whether or not cancer affected the central nervous system.
3. Record the number of secondary chronic medical conditions and list the specific diagnoses.
  - a. For cancer survivors, record information for any current chronic medical conditions; also record number of cancer-related late effects currently experienced.
  - b. For cancer survivors with neurocognitive deficits, record specific deficits.
4. Record the number of any current psychiatric conditions and list the specific diagnoses.
5. Record patient age at time of diagnosis with primary condition (years and months).
  - a. Calculate length of time the patient had been living with this condition (i.e., time between diagnosis and most recent appointment at CMH in years and months).
  - b. For cancer survivors, calculate length of time since the patient's primary cancer diagnosis.
6. For survivors of cancer:
  - a. Did cancer treatment include:
    - i. Chemotherapy?
      1. No (0)
      2. Yes (1)
    - ii. Radiation therapy?
      1. No (0)
      2. Yes (1)
    - iii. Solid tumor resection (surgery)?
      1. No (0)
      2. Yes, did not involve amputation (1)
      3. Yes, involved amputation (2)
    - iv. Immunotherapy or biologic therapy?

1. No (0)
2. Yes (1)
- v. Stem cell transplantation/bone marrow transplantation?
  1. No (0)
  2. Yes (1)
- vi. Other therapies: record \_\_\_\_\_
- vii. Record total number of therapy types.
- b. Record patient age at the time when active cancer treatment ended/remission was achieved (years and months).
- c. Did the patient experience a recurrence of cancer or a secondary cancer?
  - i. No (0)
  - ii. Yes, recurrence (1)
  - iii. Yes, secondary cancer (2)
  - iv. Yes, both recurrence of primary cancer and secondary cancer (3)
- d. If patient experienced cancer recurrence or secondary cancer, record patient age at the time when most recent cancer treatment ended/remission was achieved (years and months).
- e. Calculate duration of cancer remission (i.e., time between the end of the most recent active cancer treatment and the patient's most recent appointment at CMH) (years and months).
7. Record indicators of condition complexity:
  - a. History of surgery to treat or correct the chronic condition:
    - i. No (0)
    - ii. Yes (1)
  - b. Number of specialist physicians involved in the patient's care (record).
8. Record the following information about the patient's medication regimen at the time of the most recent appointment at CMH:
  - a. Number of medication(s) and supplements to be taken regularly
  - b. Name of each medication and supplement
  - c. Dose of each medication and supplement
  - d. Dosage form/administrative method of each medication and supplement
    - i. Oral – capsule/tablet
    - ii. Oral – gargle/mouthwash
    - iii. Oral – gums/lozenges
    - iv. Oral – liquids
    - v. Oral – powders/granules
    - vi. Oral – sublingual sprays/tabs
    - vii. Topical – creams/gels/ointments
    - viii. Topical – dressings
    - ix. Topical – paints/solutions
    - x. Topical – pastes
    - xi. Topical – patches
    - xii. Topical – sprays
    - xiii. Ear drops/creams/ointments
    - xiv. Eye drops
    - xv. Eye gels/ointments

- xvi. Nasal drops/cream/ointment
  - xvii. Nasal spray
  - xviii. Inhalation – accuhalers
  - xix. Inhalation – aerolizers
  - xx. Inhalation – metered dose inhalers (MDI)
  - xxi. Inhalation – nebulizer
  - xxii. Inhalation – oxygen/concentrator
  - xxiii. Inhalation – turbohalers
  - xxiv. Inhalation – Other dry powder inhalers (DPI)
  - xxv. Dialysate
  - xxvi. Enemas
  - xxvii. Injections – prefilled
  - xxviii. Injections – ampoules/vials
  - xxix. Pessaries
  - xxx. Patient controlled analgesia
  - xxxi. Suppositories
  - xxxii. Vaginal creams
- e. Dosing frequency of each medication and supplement:
- i. QD
  - ii. QD PRN
  - iii. BID
  - iv. BID PRN
  - v. TID
  - vi. TID PRN
  - vii. QID
  - viii. QID PRN
  - ix. Q12h
  - x. Q12h PRN
  - xi. q8h
  - xii. q8h PRN
  - xiii. q6h
  - xiv. q6h PRN
  - xv. q4h
  - xvi. q4h PRN
  - xvii. q2h
  - xviii. q2h PRN
  - xix. PRN/SOS
  - xx. On alternate days or less frequently
  - xxi. Oxygen prn
  - xxii. Oxygen <15 hrs
  - xxiii. Oxygen >15 hrs
- f. Additional directions:
- i. Break or crush tablet
  - ii. Dissolve tablet/powder
  - iii. Multiple units at one time (e.g., 2 tabs, 2 puffs)
  - iv. Variable dose (e.g., 1-2 caps, 2-3 puffs)

- v. Take/use at specified time/s (e.g., mane, nocte, 8 AM)
  - vi. Relation to food (e.g., pc, ac, with food)
  - vii. Take with specific fluid
  - viii. Take/use as directed
  - ix. Tapering/increasing dose
  - x. Alternating dose (e.g., one mane & two nocte, one/two on alternate days)
  - g. Calculate the Medication Regimen Complexity Index.
9. Record the number of components in the patient's medical regimen (at the time of the last clinic visit) that fall within the following categories:
- a. Prescribed physical exercises (e.g., physical therapy exercises, chest physiotherapy)
  - b. Dietary restrictions or specific dietary directions
  - c. Symptom monitoring or monitoring of physiological processes (e.g., blood glucose monitoring, blood pressure monitoring, prothrombin time monitoring)
  - d. Other non-medication regimen component

#### Engagement in Pediatric Healthcare and Transition Preparation Services

1. Record the number of appointments *scheduled* prior to January 1, 2015 for the patient within the CMH clinic primarily responsible for the patient's care.
  - a. Record the number of these appointments *attended* by the patient.
  - b. Calculate the percentage of appointments kept.
2. Record the percentage of all CMH appointments kept.
3. Record the number of appointments during which healthcare transition issues were discussed with the patient and/or family.
  - a. These appointments are identified by medical chart notes reporting the provision of healthcare transition education, discussion of transition to an adult-care provider, discussion of the patient's changing healthcare needs as the patient becomes an adult, discussion of how to obtain or retain health insurance as the patient becomes an adult, and/or discussion of increasing the patient's responsibility for self-care.

#### Transition Readiness

1. Record number of times and the dates on which the Transitioning Preparedness Survey (TPS) was administered to the patient.
2. For each administration of the TPS, record the following:
  - a. Patient's age at the time when the TPS was completed and TPS version
  - b. Patient's responses to each TPS item



## Appendix B. Medication Regimen Complexity Index (MRCI)

George, Phun, Bailey, Kong, & Stewart (2004)

Total no. of medications (including prn/sos medications): \_\_\_\_\_

### Instructions

- MRCI applies only to prescribed medications. All entries are to be made only based on information on the label or drug chart (at the time of dispensing or discharge). No assumptions are to be made based on clinical judgment.
- There are three sections in the scale. Complete each section before proceeding to the next. At the end, add the scores for the three sections to give the MRCI.
- If the same medication (same brand and same dosage form) is present more than once in different strengths in a regimen (e.g., Marevan 5mg, 3mg, and 1mg mdu), it is still considered as one medication.
- In cases where the dosage is optional, choose the dosing instruction with the smallest dose/frequency. (e.g., Ventolin MDI 1-2 puffs, 2-3 times daily will get weightings for 'metered dose inhalers', 'variable dose' and 'twice daily'; but not for 'multiple units at one time')
- In certain cases the dosing frequency needs to be calculated (e.g., Ranitidine 1 mane and 1 nocte is 1 twice daily)
- It is possible that with certain 'used as directed' instructions, the regimen will not get a score under dosing frequency (e.g., Prednisolone 5mg mdu)
- If there is more than one dosing frequency direction, they should be scored for all the dosing frequency directions (e.g., Ventolin MDI 2 puffs bd and prn, will get scores for 'metered dose inhalers', 'multiple units at one time', 'twice daily' as well as 'prn')
- Instances where two or more medications are mutually exclusive, they need to be scored twice or more as prn with the recommended dosing frequency (e.g., Ventolin MDI or Ventolin nebulizer twice daily will get scores for both 'metered dose inhalers' and 'nebuliser' under dosage forms, but needs to be scored two times for 'twice daily prn')
- In cases where there is no matching option, choose the closest option (e.g., six times daily could be considered as 'q4h')

[A] Circle the weighting corresponding to each dosage form (ONCE ONLY) present in the regimen.

	Dosage Forms	Weighting
<b>ORAL</b>	Capsules/Tablets	1
	Gargles/Mouthwashes	2
	Gums/Lozenges	2
	Liquids	2
	Powders/Granules	2
	Sublingual sprays/tabs	2
	Creams/Gels/Ointments	2
	Dressings	3
	Pains/Solutions	2
	Pastes	3
<b>TOPICAL</b>	Patches	2
	Sprays	1
	Ear drops/creams/ointments	3
	Eye drops	3
	Eye gels/ointments	3
	Nasal drops/cream/ointment	3
	Nasal spray	2
	Accuhalers	3
	Aerolizers	3
	Metered dose inhalers (MDI)	4
<b>INHALATION</b>	Nebuliser	5
	Oxygen/Concentrator	3
	Turbohalers	3
	Other DPIs (dry powder inhaler)	3
	Dialysate	5
	Enemas	2
	Injections: Prefilled Ampoules/Vials	3
	Pessaries	4
	Patient controlled analgesia	3
	Suppositories	2
<b>OTHERS</b>	Vaginal creams	2
	<b>Total for Section A</b>	

**[B]** For each medication in the regimen tick a box [x] corresponding to the dosing frequency. Then, add the no. of [x] in each category and multiply by the assigned weighting. In cases where there is no exact option, choose the best option.

Dosing Frequency	Medications										Total	Weighting	x No. of
Once daily												1	
Once daily prn												0.5	
Twice daily												2	
Twice daily prn												1	
Three times daily												3	
Three times daily prn												1.5	
Four times daily												4	
Four times daily prn												2	
q12h												2.5	
q12h prn												1.5	
q 8h												3.5	
q 8h prn												2	
q 6h												4.5	
q 6h prn												2.5	
q 4h												6.5	
q 4h prn												3.5	
q 2h												12.5	
q 2h prn												6.5	
prn/sos												0.5	
On alternate days or less frequently												2	
Oxygen prn												1	
Oxygen <15hrs												2	
Oxygen >15hrs												3	
<b>Total for Section B</b>													

**[C]** Tick a box [x] corresponding to the additional directions, if present in the regimen. Then, add the no. of [x] in each category and multiply by the assigned weighting.

Additional Directions	Medications										Total	Weighting	x No. of
Break or crush tablet												1	
Dissolve tablet/powder												1	
Multiple units at one time (e.g., 2 tabs, 2 puffs)												1	
Variable dose (e.g., 1-2 caps, 2-3 puffs)												1	
Take/use at specified time/s (e.g., mane, nocte, 8 AM)												1	
Relation to food (e.g., pc, ac, with food)												1	
Take with specific fluid												1	
Take/use as directed												2	
Tapering/increasing dose												2	
Alternating dose (e.g., one mane & two nocte, one/two on alternate days)												2	
<b>Total for Section C</b>													

<b>Total for Section A</b>	
<b>Total for Section B</b>	
<b>Total for Section C</b>	
<b>Medication Regimen Complexity (sum)</b>	

Appendix C: Transitioning Preparedness Survey 12-14 Version



**Transitioning Preparedness Survey (ages 12-14)**

Patient Label Here

**Patient Name / MR#:**

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Section 1 - Knowledge <i>(For each of the following statements select the answer that best describes you:)</i>		Yes! I can do this	I want to learn how to do this	Someone else will have to do this. Who?
1.	I can describe my medical problem.			
2.	I know the names of my doctors and nurses.			
3.	I can tell someone what health insurance plan I have.			
4.	I can list my medications.			
5.	I know when to take my medications.			

Section 2 - Skill <i>(For each of the following statements select the answer that best describes you:)</i>		Yes! I can do this	I want to learn how to do this	Someone else will have to do this. Who?
1.	I keep a list of telephone numbers of my doctors and nurses.			
2.	I can answer questions the doctor asks.			
3.	I keep a list of my medical problems.			
4.	I can tell my family when I am sick enough to need a doctor visit.			
5.	I carry my health insurance card every day.			
6.	I can tell others how to help me when I need to.			

Section 3 - Taking Charge <i>(For each of the following statements select the answer that best describes you:)</i>		Yes	No
1.	I want to take care of my health by myself.		
2.	I have support from my parents or friends.		
3.	I am excited to move to adult care.		
4.	It is important for me to have an adult doctor.		

Goals <i>(to be accomplished before the next appointment)</i>	
1.	
2.	
3.	
4.	

Please include any comments or questions about any of the items in the space below:

**Primary Sub Specialist:** \_\_\_\_\_

**Other Specialists:** \_\_\_\_\_

**Primary Care Provider:** \_\_\_\_\_

## Appendix D: Transitioning Preparedness Survey 15-17 Version



### Transitioning Preparedness Survey (ages 15-17)

Patient Label Here

Patient Name / MR#: \_\_\_\_\_

Section 1 - Knowledge (For each of the following statements select the answer that best describes you:)		Yes! I can do this	I want to learn how to do this	Someone else will have to do this. Who?
1.	I can describe my medical problem.			
2.	I can list my medical history.			
3.	I know my medical providers or specialists			
4.	I know health insurance is important.			
5.	I can list my medications.			
6.	I can tell someone how my medications work.			

Section 2 - Skill (For each of the following statements select the answer that best describes you:)		Yes! I can do this	I want to learn how to do this	Someone else will have to do this. Who?
1.	I keep a list of my medicines.			
2.	I take my medicines by myself			
3.	I keep a list of important medical contacts.			
4.	I can answer questions the doctor asks.			
5.	I keep a list of my medical problems.			
6.	I can recognize an emergency for my health problem.			
7.	I carry my health insurance card every day.			
8.	I can tell others how to help me when I need to.			

Section 3 - Taking Charge (For each of the following statements select the answer that best describes you:)		Yes	No
1.	I want to take care of my health by myself.		
2.	I have support from my parents or friends.		
3.	I am excited to move to adult care.		
4.	It is important for me to have an adult doctor.		

Goals (to be accomplished before the next appointment)	
1.	
2.	
3.	
4.	

Please include any comments or questions about any of the items in the space below:

**Primary Sub Specialist:** \_\_\_\_\_

**Other Specialists:** \_\_\_\_\_

**Primary Care Provider:** \_\_\_\_\_

## Appendix E: Transitioning Preparedness Survey 18+ Version



### Transitioning Preparedness Survey (ages 18+)

Patient Label Here

Patient Name / MR#:

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Section 1 - Knowledge (For each of the following statements select the answer that best describes you:)		Yes! I can do this	I want to learn how to do this	Someone else will have to do this. Who?
1.	I can describe my medical problem.			
2.	I can list my medical history.			
3.	I can talk about how my medical problem could affect my sex life.			
4.	I can talk about how alcohol, drugs or cigarettes could affect my medical problem.			
5.	I can tell someone what health insurance plan I have.			
6.	I can list my medications.			
7.	I can tell someone how my medications work.			

Section 2 - Skill (For each of the following statements select the answer that best describes you:)		Yes! I can do this	I want to learn how to do this	Someone else will have to do this. Who?
1.	I refill my prescriptions by myself.			
2.	I take my prescriptions by myself.			
3.	I can get to my doctor appointments on my own.			
4.	I talk with my doctor by myself.			
5.	I keep a list of my medical problems.			
6.	I can recognize an emergency for my health problem.			

Section 3 - Taking Charge (For each of the following statements select the answer that best describes you:)		Yes! I can do this	I want to learn how to do this	Someone else will have to do this. Who?
1.	I can take care of my health by myself			
2.	I have support from my parents or friends.			
3.	I am excited to move to adult care.			
4.	It is important for me to have an adult doctor.			

Goals (to be accomplished before the next appointment)	
1.	
2.	
3.	
4.	

Please include any comments or questions about any of the items in the space below:

**Primary Sub Specialist:** \_\_\_\_\_

**Other Specialists:** \_\_\_\_\_

**Primary Care Provider:** \_\_\_\_\_



## Appendix F: Data Collection Form for Follow-up Calls to Adult Participants

Research study participant ID number: \_\_\_\_\_

Researcher's Printed Name: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_

Date(s) of Phone Call(s): \_\_\_\_\_

Date of Data Entry: \_\_\_\_\_

Section A

Date of last CMH appointment (from medical chart review): \_\_\_\_\_

Age of young adult patient at time of phone call: \_\_\_\_\_

Who responded to the follow-up questions? (select one)

Young adult

Parent/caretaker of young adult: specify \_\_\_\_\_

Other: specify \_\_\_\_\_

Section B

Adult primary care provider (PCP):

Provider's name: \_\_\_\_\_

Name of clinic/office/practice/institution: \_\_\_\_\_

Phone number and address: \_\_\_\_\_

Record the following information for all outpatient, adult primary care appointments (including appointments with PCPs other than the one CMH referred):

Date of appointment:	PCP name:	Clinic name:	Appt attended?
			Yes / No
			Yes / No
			Yes / No
			Yes / No
			Yes / No
			Yes / No
			Yes / No
			Yes / No
			Yes / No
			Yes / No

Was the young adult referred to any adult-care specialists? (circle one) Yes / No

- If yes, continue to Section C; if not, skip to Section D

### Section C

Record the following information for all adult-care specialists to whom CMH referred the young adult (from medical chart review):

Specialty:	Specialist's name:	Clinic/hospital name:	Phone number:	Address:

Record the following information for all outpatient, adult specialty care appointments (including appointments with specialists other than the one(s) CMH referred):

Date of appointment:	Specialty	Specialist's name:	Clinic name:	Appt attended?
				Yes / No
				Yes / No
				Yes / No
				Yes / No
				Yes / No
				Yes / No
				Yes / No
				Yes / No
				Yes / No
				Yes / No
				Yes / No

### Section D

Young adult's level of satisfaction with the healthcare transition process: (circle one)

*0 = entirely dissatisfied, 1 = moderately dissatisfied, 2 = mildly dissatisfied,*

*3 = mildly satisfied, 4 = moderately satisfied, 5 = entirely satisfied*

Young adult's suggestions for improving the transition process:

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