

ATHABASCA UNIVERSITY

MEASURES OF TRANSITION READINESS IN ADOLESCENTS AND YOUNG ADULTS
WITH CHRONIC DISEASE: A SYSTEMATIC REVIEW

BY

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A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF NURSING

FACULTY OF HEALTH DISCIPLINES
CENTRE FOR NURSING AND HEALTH STUDIES

ATHABASCA UNIVERSITY

APRIL, 2018

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Approval of Thesis

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**MEASURES OF TRANSITION READINESS IN ADOLESCENTS AND YOUNG ADULTS
WITH CHRONIC DISEASE: A SYSTEMATIC REVIEW**

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Master of Nursing

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Abstract

The transition from pediatric to adult healthcare for adolescents with chronic illness has emerged as a critical period in long-term health outcomes. Suitable transition readiness measures are necessary for healthcare professionals to assess the readiness to transition of their patients and improve transition outcomes. Currently, there is no consensus about well-validated transition readiness measurements. The goal of this thesis was to systematically review the literature for transition-readiness tools for adolescents with chronic health illnesses published in peer-reviewed journals. Forty-eight articles, representing 19 different tools, were included in the review. Ten of the tools were disease-specific; nine were disease-neutral. Eight measures were “well-established assessments” (Cohen criteria). Overall, the Transition Readiness Assessment Questionnaire remains the best well-validated measure of transition readiness available. In conclusion, even after the release of the national practice guidelines and ongoing policy development, there continues to be only slow movement towards achieving a “gold standard” measure of transition readiness.

Keywords: transition readiness, adolescents and young adults, chronic illness

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CHAPTER 1 – INTRODUCTION

Surgical and medical advancements have improved the likelihood of chronically ill children surviving into adulthood. Transfer from the specialized pediatric to specialized adult care can be challenging to the family and client as well as the teams of healthcare providers. Without adequate support, many adolescents and young adults (AYAs) are unable to transfer to adult healthcare successfully. Transition readiness measures and tools have been developed to enable and encourage opportunities for increasing health independence and tracking AYAs through the transition process. In addition, they identify AYAs at risk of loss to follow-up (LTFU). LTFU is defined as no patient contact with a healthcare provider for more than three months among patients who have not died or transferred from pediatric to adult healthcare (Stewart et al., 2017). However, the development of measures to facilitate the transition for AYAs with chronic health conditions are in the early phases, and there is a link between poor patient outcomes and a lack of transitional care and support (Jensen et al., 2017). To ensure a successful transition, self-management of chronic conditions is crucially important and influences health outcomes in adult life (Jensen et al., 2017; Schwartz, Daniel, et al., 2014; Stinson et al., 2014). A successful transition process facilitates enhanced and increased empowerment and self-management, whereas poorly executed transitions may lead to inappropriate healthcare utilization, non-adherence to medical treatments and difficulty establishing a connection with an adult medical provider (Schwartz, Daniel, et al., 2014).

Statement of the Problem

Currently, there is no consensus in the literature about well-validated measures of transition readiness in AYAs transitioning to adult healthcare. Most published studies aiming to bring awareness to transition readiness measures fail to address the impact of transition on health

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outcomes, patient satisfaction and cost; the “triple aim” (Berwick, Nolan & Whittington, 2017; Gabriel, McManus, Rogers & White, 2017; Prior, McManus, White, & Davidson, 2014).

Significance of Knowledge Synthesis Project

Measures of transition readiness for transfer from pediatric to adult healthcare is a fast-growing field, and synthesis of this research is imperative so that the most recent evidence can be applied by researchers and clinicians. The aim of this study was to systematically review peer-reviewed articles on transition readiness measures for AYAs with chronic illnesses and to assess the methodological measurement qualities of each measure. The primary researcher systematically reviewed and synthesized the published literature since 2014, when Stinson and colleagues from The Hospital for Sick Children in Toronto, Canada (Stinson et al., 2014), as well as researchers Zhang, Ho and Kennedy (2014) and Schwartz et al. (2014), completed simultaneous systematic review of transition readiness measures. Their reviews showed the already growing and diverse field of transition readiness measures.

Definition of Terms

For the purposes of this study the following terms are defined as:

Adolescent and young adult (AYA) refers to those between the ages of 11 and 25.

Knowledge synthesis, also known as knowledge translation, is a process that may include dissemination and synthesis, to improve the health of Canadians, while strengthening the healthcare system and providing more effective services and products (Graham, 2012).

Loss to follow-up (LTFU): is defined as no patient contact with a healthcare provider for more than three months among adolescents and young adults who have not died or transferred from pediatric to adult healthcare (Stewart et al., 2017).

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Self-management is the taking on of responsibility for one's chronic condition; including but not limited to, behaviours such as organizing medications, calling the pharmacy for refills, booking healthcare appointments, adhering to healthcare provider instructions, communicating independently with healthcare team and understanding drug coverage and costs (Ferris, Cohen, et al., 2015).

Systematic review, as defined by the Cochrane Handbook (Higgins & Green, 2011), is a form of knowledge synthesis; a search where the author endeavours to identify all studies that meet specified eligibility criteria. It is a summary of the results of published and carefully designed healthcare studies, providing a specific level of evidence on the topic of the review (e.g., health-related measure, and effectiveness of healthcare interventions).

Transfer refers to the actual move from pediatric healthcare to adult healthcare (Stinson et al., 2014).

Transition encompasses the purposeful and planned movement of youth with chronic medical conditions from pediatric to adult-orientated healthcare systems (Blum, Garrell, & Hodgman, 1993).

Transition readiness depicts the readiness of an AYA to prepare for, enter, continue and complete a successful transfer from specialized pediatric to specialized adult healthcare (Schwartz, Daniel, et al., 2014; Stinson et al., 2014; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004). Transition readiness is measurable, and involves multiple components, including the AYA's knowledge of condition, skills for self-management, maturity, independence and autonomy in managing their health (Schwartz, Daniel, et al., 2014; Van Staa & Sattoe, 2014).

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Beginning and Ending Dates

The protocol for this systematic review of transition readiness measures was developed in January 2017, with search dates of 2014-01-01 to 2017-02-26. This search was re-run in January 2018 to identify articles published between 2017-02-26 and 2018-03-31. During the second search, the original search dates were included, therefore the databases were searched from 2014-01-01 to 2018-03-31.

CHAPTER 2 - LITERATURE REVIEW

The transition from specialized pediatric to specialized adult healthcare services for a patient with chronic illness, has emerged as a critical period impacting long-term health outcomes (Jensen et al., 2017; Stinson et al., 2014). The transition between care providers and settings puts AYAs at risk for inadequate follow-up and they may even be lost to follow-up (Schwartz, Daniel, et al., 2014). Facilitating an effective transition period and successful transfer is the responsibility of pediatric and adult providers; transition programming is a term that encompasses multiple components to facilitate and support successful transfer.

Transition timing and programming has often been based around an AYA's chronological age however recent shifts in transitional assessment and transfer have assessed developmental readiness which is a culmination of an AYA's functional age physically, emotionally, cognitively and socially (Moynihan, Saewyc, Whitehouse, Paone, & McPherson, 2015). In June 2016, the Canadian Association of Paediatric Health Centres (CAPHC) Transition Community of Practice (CoP) released the *Guidelines for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach*. Its primary aims included identifying tools and resources for stakeholders in the transition of adolescents to adult healthcare. In this set of guidelines, it is recognized that there is a growing body of literature, and the guidelines recommended the development of consistent measures to use across conditions and sites and utilize both qualitative and quantitative assessment approaches. Suitable transition readiness measures are necessary, allowing healthcare professionals to assess the readiness of their patients to transition and target areas where interventions are needed to improve transfer outcomes.

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Transition

A transition is a purposeful, planned movement of youth with chronic medical conditions from pediatric to adult-orientated healthcare systems (Blum et al., 1993). Kaufman and Pinzon (2007), in collaboration with The Canadian Paediatric Society released a position statement, describing the goal of transition care as being “to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound before and throughout the transfer of youth into the adult system” (p.786). The literature stresses that the transfer from pediatric care to adult care is a onetime event; however, the transitional period is a much longer process (Gilleland, Amaral, Mee, & Blount, 2012; Lerret et al., 2012; McDonagh, 2005; McDonagh & Kelly, 2007). The published literature consistently shows that most AYAs, including those with special healthcare needs, and their parents, receive limited or no transition preparation, transfer assistance, and facilitated integration into adult care (Gabriel et al., 2017). Transition readiness is a component of larger concern, which includes these elements; however, they are not discussed in detail in this study.

Transition Readiness

Transition readiness and the transitional period in AYAs with chronic health conditions has been studied in the literature extensively (Annunziato, Freiburger, et al., 2014; Dobbels et al., 2010; Gilleland, Amaral, Mee & Blount 2012; McDonagh & Kelly, 2007; Zelikovsky, Schast, Palmer, & Meyers, 2008). Despite calls for evidence-based assessment of AYA transition readiness and initiatives for improving transition from pediatric care to adult care, few validated measures exist that assess and track transition readiness for AYA patients with chronic health conditions (Jensen et al., 2017; Schwartz, Hamilton, et al., 2017; Stinson et al., 2014). Researchers have identified the factors negatively and positively impacting the AYA’s readiness

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to transition and identified the importance of best practice guidelines and transition-focused clinics. The American Academy of Pediatrics (AAP) and American Academy of Family Practitioners (AAFP) (2011) recommend practitioners plan a longitudinal process to prepare AYAs to become independent, enabling them to assume responsibility for their chronic care management after transfer to adult services. In the literature it is suggested that AYAs will benefit from engagement with their providers about self-management behaviours, as well as, increased health management responsibility, in addition to guidance targeting specific behaviors related to transition readiness (e.g. physical, mental and psychosocial) (Beal et al., 2016; Gabriel et al., 2017; Polfuss, Babler, Bush, & Sawin., 2015).

Responsive action to the 2011 AAP and AAFP policy statements has been slow. Experts in the field continue to report that there is limited evidence of strengthened psychometric properties of transition readiness measures, and despite the recommendation for valid and reliable transition readiness tools, wide variations in care and a lack of guidance on transition and transfer protocols remain a barrier (Agarwal, Garvey, Raymond, & Schutta, 2017; Jensen et al., 2017). Furthermore, it continues to be challenging to define and examine transition readiness due to the lack of a core set of transition measures and consistency in the literature (Schwartz, Daniel, et al., 2014). There are, however, several helpful published systematic reviews.

Previous Systematic Reviews

Systematic reviews by Stinson et al. (2014), Zhang, Ho and Kennedy (2014), and Schwartz, Daniel, et al. (2014) demonstrated the diversity of transition measures, recommending the ongoing development of new measures and further validation of current measures to improve clinical practice.

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Stinson et al. (2014) systematically reviewed the literature from 1950 to 2012; they identified 14 articles that used eight transition readiness and six satisfaction measures for assessment of AYAs during the transition period. Stinson et al. (2014) applied Cohen's criteria for evidenced-based assessment and concluded that no high-quality readiness measure existed, regarding reliability and validity. The Cohen criteria provides a three-level ranking system designed to critique and analyze measures (Cohen, La Greca, et al., 2006). Stinson acknowledged that the review was limited to measures that reflected the conceptual definition of transition satisfaction developed by the study authors.

Zhang et al. (2014) from the University of New South Wales, Sydney, Australia, reviewed the literature up until 2014 for transition readiness tools only. They identified ten assessment tools, classified them by disease-specific and disease-neutral, and assessed them as per a standardized checklist. Zhang et al. (2014) concluded that the Transition Readiness Assessment Questionnaire (TRAQ) was the most reliable transition readiness measure. They identified similar limitations in the published literature as Stinson, the main one being the difficulty establishing criterion validity because there is no gold standard measure of transition readiness.

Schwartz, Daniel, et al. (2014) from the Children's Hospital of Philadelphia, USA, provided a systematic review of published measures of transition readiness, and unlike Zhang et al. (2014) and Stinson et al. (2014), Schwartz, Daniel, et al. (2014) also provided recommendations for future research and measure development. Schwartz, Daniel, et al. (2014) utilized well-developed inclusion criteria, resulting in the review of ten measures. They offered recommendations and considerations for future researchers, including grounding measures in theory, testing measures with diverse populations, and testing psychometric properties with appropriate sample sizes.

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Researchers agree that there must be further testing and validation of existing measures, as well as, the creation of measures to establish evidence-based and empirically-tested tools (Schwartz, Daniel, et al., 2014; Stinson et al., 2014; Zhang et al., 2014). These reviews showed the rapidly growing body of literature and the need for ongoing synthesis.

Most published studies describing transition readiness were aiming to bring awareness to transition readiness measures; however, did not question the impact of transition on health outcomes, patient satisfaction, and cost (Gabriel et al., 2017; Prior et al., 2014). The lack of valid measures that are sensitive to this developmental period hinders the ability to adequately assess unique problems, identify targets, track changes across the AYA period and evaluate outcomes (Schwartz, Hamilton, et al., 2017). Many of the measures currently available are not theoretically informed, and stakeholder feedback was not a part of the development (Schwartz, Hamilton, et al., 2017). Schwartz, Hamilton, et al. (2017) introduced the theoretically informed Socio-Ecological Model of AYA Readiness for Transition (SMART) to address this gap.

The Transition Readiness Inventory (TRI) item pool, developed by Schwartz, Hamilton, et al., (2017) and based on SMART, represents the first theoretically informed transition readiness tool. Also, research by Prior et al. (2014) and Davis, Brown, Taylor, Epstein, and McPheeters (2014) has shown the diversity of transition interventions and the broad spectrum of criteria used to evaluate them. Currently, regardless of the condition, there is no consensus in the literature about well-validated measures and tools that assess transition readiness in young adults transitioning from pediatric healthcare to adult healthcare. Researchers agree, there remain too few AYA-specific measures (Devine, Monaghan, & Schwartz, 2017; Schwartz, Daniel, et al., 2014). This study aimed to systematically review transition-readiness measures for adolescents

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with chronic health illnesses published in peer-reviewed journals since 2014 and assess the methodological measurement qualities of each tool.

Overview of Current Measures

Transitional programs continue to use various measures and tools to improve the transfer process, disease-specific or not, most of which are of limited scope of assessment, not specific to AYA needs and not validated (Gabriel et al., 2017; Jensen et al., 2017; Johnson et al., 2015). Measures have different properties, including disease-specific, disease-neutral, outcomes measured, who completed the survey, format and languages available. There are several transition readiness measures in the literature. The specific measures identified in the systematic reviews published by Schwartz, Daniel, et al. (2014); Stinson et al. (2014); and Zhang et al. (2014) include the TRAQ (Sawicki, Lukens-Bull, et al., 2009), the University of North Carolina (UNC) TRxANSITION Scale (Ferris, Harward, et al., 2012), and the Readiness to Transition Questionnaire (RTQ) (Gilleland et al., 2012).

Research by Tepper, Zaner, and Ryscavage (2017) recommends AYAs living with chronic illness be included in the development and evaluation of transition protocols to ensure that the definition of successful transition reflects all of the stakeholders in the transition process. The administration method and format of the tool is an important aspect to consider during development. Tools may be administered by a trained healthcare provider or completed independently by the AYA, referred to as self-report. Self-report has been seen as a limitation by researchers, as the AYA perceptions of quality of care may not reflect actual quality of care received (Mackie, Islam, et al., 2014; Okumura et al., 2014; Treadwell et al., 2016a). To overcome this, researchers recommend cross-referencing patient responses with medical records and multiple perspectives, such as parent and healthcare provider, throughout the process

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(Okumura et al., 2014). Tools may be administered in a written format during a clinic visit, or through an online format. Researchers may mail out surveys or have them completed during a routine clinic visit.

Measures may be used longitudinally or at one point in time as per a cross-sectional design. Researchers agree, longitudinal studies showing change and potential correlations between, for example, healthcare transition knowledge and readiness, are superior to cross-sectional designs (Eluri et al., 2017; Grady et al., 2018; Stollon, Zhong, et al., 2017). Transitional programs continue to use various interventions and measures to improve the transfer process, disease-specific or not, most of which are of limited scope and generalizability (Gabriel et al., 2017; Jensen et al., 2017; Johnson et al., 2015).

Summary of Gaps

Despite the constantly growing body of literature addressing transition measures, researchers continue to identify gaps in implementation practice. Clemente, Leon, Foster, Carmona and Minden (2017) found less than 10% of pediatric rheumatologists use a specific transition measure, reflecting the informal approach that still exists to transition in most healthcare centers. Garvey et al. (2013) surveyed 65 adults with Type 1 diabetes and found less than 15% had a specific transition visit, received written transitional materials or met the adult provider before the transition. Hilderson et al. (2009) surveyed pediatric cardiologists in the United States and Europe. Of the 69 centers surveyed, one-quarter did not transfer their patients to adult care. According to the researchers, this indicated that the centers continued to care for the patients once they had reached adulthood, and or the patients were discharged without referral to an adult healthcare provider for continued follow-up (Hilderson et al., 2009). Of the programs that transferred their patients, only 30% provided education materials.

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Regardless of the chronic condition, without a well-designed transition measure, AYAs are at an increased risk for loss to follow-up during the challenging transfer period with associated morbidities (Foster et al., 2017; Gurvitz et al., 2013; Ramos et al., 2017; Yeung, Kay, Roosevelt, Brandon, & Yetman, 2008). There is an ongoing need for research to provide an evidence base to inform models of care, identify relevant outcome measures and the cost-effectiveness of transitional care programmes as a complex intervention (Foster et al., 2017). Clinicians have the potential to feel more confident beginning the transfer process with adolescents if they have access to appropriate transition readiness measures. Research is needed to identify all the transition readiness tools for adolescents and begin developing a consensus in the literature.

Conceptual Frameworks

In their systematic review, Schwartz, Daniel, et al., (2014) emphasized the importance of grounding measures in theory to support the validity of the new measures. Current tools do not capture socio-ecological factors that are theoretically important for transition readiness (Schwartz, Hamilton, et al., 2017; Szalda et al., 2017). The Triple Aim and Socio-Ecological Model of AYA Readiness for Transition (SMART) may lead researchers to developing a core set of measures by looking at modifiable and non-modifiable variables. For the development of future successful transition readiness tools, creative thinking beyond health care skills and knowledge will be crucial (Schwartz, Hamilton, et al., 2017).

The Triple Aim

Transition readiness measures are inconsistently evaluated in terms of their influence on population health, patient experience, and cost (Prior et al., 2014). The Triple Aim, developed by the Institute for Healthcare Improvement, is a conceptual framework organized around three goals: (1) improve the individual experience of healthcare; (2) improve the health of populations;

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and (3) reduce the per capita cost of care (Prior et al., 2014). By understanding how measures of transition readiness may relate to experience of care, population health, and cost, we may come to a more unified approach and a core set of measures for evaluating healthcare transition interventions (Prior et al., 2014).

Socio-Ecological Model of AYA Readiness for Transition (SMART)

The theoretically informed SMART, developed by Schwartz, Tuchman, et al. (2011), incorporates multiple stakeholders and pre-existing factors, such as disease, developmental status, age, gender, ethnicity, access to healthcare and education level. The model measures more than patient age, knowledge and skills; it addresses modifiable factors that are amenable to intervention, such as goals and motivation; relationships and communication; and beliefs and expectations. SMART incorporates a socio-ecological framework, emphasizing the critical role of subjective factors, and distinguishes variables more amenable to interventions (Schwartz, Brumley et al., 2013; Schwartz, Hamilton, et al., 2017). Currently, measures of transition readiness place little emphasis on multiple components of transition readiness that can be targeted and/or changed to help improve the transition.

Objective

Currently, there is no consensus in the literature about well-validated measures that measure transition readiness in AYAs transitioning from pediatric healthcare to adult healthcare. This synthesis project aimed to systematically review transition-readiness measures for AYAs with chronic illnesses published in peer-reviewed journals since 2014 and assess the methodological qualities of each tool. This review classified measures using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, and the Cohen criteria (Cohen, La Greca, et al., 2006). The Cohen criteria provides a means of

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evaluating the methodological quality of the tool based on number of publications, accessibility of the tool and psychometric evaluation. The strengths and limitations of each measure were evaluated to make recommendations for future research and measure development.

Research Question

What are the strengths and limitations of the validated and non-validated measures pertaining to adolescent and young adult (AYA) transition readiness from pediatric to adult healthcare found in the literature from 2014 to present?

CHAPTER 3 - METHODS

The following section provides an overview of the inclusion and exclusion criteria, search techniques for identification of studies, search strategy, data extraction and synthesis to be used in the present synthesis study. By critically evaluating and synthesizing the literature, a systematic review aims to answer precise questions (MacLure, Paudyall, & Stewart, 2016). The analysis of a systematic review is intended to inform readers what is current knowledge, where are the gaps in the literature, and to make recommendations for future practice (Grant & Booth, 2009).

Protocol and Registration

Details of the protocol for this systematic review have been registered with PROSPERO. Prospero is an international database of prospectively registered systematic reviews in many different fields, where there is a health-related outcome. The protocol can be accessed at http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018083526 or available by request.

Eligibility Criteria

To be eligible for inclusion in this review, articles met the following criteria: (1) published in a peer-reviewed journal between 2014-01-01 and 2018-03-31 (2) developed, discussed or assessed measures/tools assessing transition readiness in an AYA aged 11 to 25 with chronic illness, before or after the transfer from pediatric to adult care; and (3) discussed the development and psychometric properties of the measure. Also, there was no exclusion based on study design; both qualitative and quantitative research articles were included. There continues to be no standardized definition of transition readiness; therefore, to prevent limiting the studies

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included in the review, articles were included that directly and indirectly measured transition readiness.

The following types of publications were excluded from the review: guidelines, dissertations, reports, commentaries, integrative reviews, systematic reviews, literature reviews or abstracts. Articles not available in English were not included in the study; articles that had been translated into English were included.

Identification of Articles for Screening

Information Sources

The primary author and thesis student (SP) conducted electronic searches in consultation and collaboration with a Reference Services Librarian at Athabasca University and thesis committee member (PM). With previous systematic reviews on measures of transition readiness ending their searches between October 2012 and December 2013, this systematic review included literature published from January 1, 2014 to the March 31, 2018. The primary author searched multiple academic databases, including Pubmed, Cumulative Index of Nursing and Allied Health Literature (CINHAL), Athabasca University's Library's Discover, and Google Scholar, which is an online broad search engine. The primary author also contacted authors of measures for additional information as needed.

Search Strategy

Each database was searched using pre-determined search terms. Search terms included transition concepts, chronic illness concepts and survey and questionnaire concepts. These search terms were combined.

Transition concepts using text included: "transition to adult care" OR "transitions to adult care" OR "transition readiness" OR "transition strategies" OR "transitional care" OR "readiness

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to transition" OR "care transitions" OR "transition strategy" OR "transitions of care" OR "transition of care" OR "transitioning to adult care" OR "patient transition" OR "transition from paediatric to adult care" OR "transition from pediatric to adult care" OR "care transition strategy" OR "care transition strategies" OR "readiness for transfer" OR "transition program" OR "transitional program" OR "transition process" OR "transition of pediatric patients" OR "transition of paediatric patients" OR "transition programmes" OR "transition of patients" OR "health-care transition" OR "healthcare transition" OR "health care transition" OR "preparation for transition" OR "transition of pediatric to adult healthcare".

Chronic illness concepts using text included: "chronic illness" OR "chronically ill" OR "chronic health conditions" OR "chronic health condition" OR "type 1 diabetes" OR "cystic fibrosis" OR "congenital heart defects" OR "medically and socially complex youth" OR "chronic kidney disease" OR "sickle cell disease" OR "sickle cell" OR "childhood cancer" OR "cancer" OR "juvenile idiopathic arthritis" OR "diabetes" OR "asthma" OR "epilepsy" OR "congenital heart disease" OR "transplant". Finally, surveys and questionnaires using text included: "transition planning tool" OR "patient experience measure" OR survey OR questionnaire assessment OR measure OR "randomized response technique" OR surveys OR questionnaires OR assessments OR measures OR "measure-satisfaction" OR "measurement framework" OR "experience measure."

This synthesis project was based on the PRISMA protocol; this stands for Preferred Reporting Items for Systematic Reviews and Meta-Analyses. The PRISMA flow diagram provides a visual of the flow of information through the different phases of the review process. This diagram maps out studies included, duplicates, and a brief overview of reasons for exclusion. The citation management tool, RefWorks, was used to export and manage articles. We

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used REDCap (Research Electronic Data Capture) to record all screening and extraction data. There were two types of subsequent searches conducted after reviewing the results of the primary search. The primary author manually searched appropriate journals, and or, conducted an author search using the names of authors who had conducted research on measures of transition readiness. The search strategy, timeframe, and full list of keywords was organized in the primary author's Project Notebook (see Appendix A) and provides a comprehensive audit trail.

Rigour

The systematic review was conducted using a validated search strategy. The primary author was the primary reviewer, as this is the author's thesis research. The two secondary reviewers were the thesis co-supervisors (GR and KP). The reviewers worked independently of each other. The primary reviewer was responsible for the overall conduct of the review and for keeping the review process focused and on schedule. All reviewers had a good understanding of the inclusion and exclusion criteria, and how to use the citation management and data extraction tools. A fourth member of the committee was available as a third reviewer if needed to provide resolution for any disagreement between reviewers; this did not occur.

The primary and secondary reviewers examined each computer search and relevant additional studies to identify potentially eligible articles, based on the study titles and abstracts, using the inclusion and exclusion criteria outlined. The primary author and secondary reviewers screened all articles in full that met the criteria and consensus between reviewers determined eligibility.

A protocol was developed and referenced throughout the systematic review by the primary author and secondary reviewers. The protocol was essential for the rigorous implementation of

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the review. The author and reviewers adhered as strictly as possible to the protocol, and it served as a roadmap providing the essential procedures for conducting the review. The protocol is referred to as the Project Notebook and includes search strategies, acknowledgments, conflicts of interest, identification of studies, and methods of review. Also, the Project Notebook is available as an audit trail and contains documentation of all processes, so others may replicate this review.

Screening for Study Selection

Before beginning the screening, the primary reviewer utilized a citation management tool and removed all duplicates from the records identified through database searching and other sources. Initial screening, Phase One, was a review of titles only by the primary reviewer. The primary reviewer accomplished this by exporting the citation and abstract information from RefWorks, the data management tool, into Excel and removed any articles that did not fit the inclusion criteria based on the title. The remaining articles moved to Phase Two of screening.

Screening Phase Two included the independent review of all search titles and abstracts by at least two reviewers (see Appendix B for screening tool). Before completing a full review, ten percent of the articles were reviewed to ensure inter-rater reliability at this stage. Screening Phase Two began once there was at least an 80% level of reliability between the primary reviewer and secondary reviewers. This met the acceptable level of 80% reliability (Furlan, Singh, Hsieh, & Fehlings, 2011, p. 1339). The primary reviewer collated all decisions and calculated the reliability of screening Phase Two. The primary reviewer sent a table of the results of the screening to the secondary reviewers, and a consensus meeting took place to manage the articles for which there was disagreement about inclusion or exclusion. During the consensus meeting, disagreements were discussed, articles where disagreement occurred were automatically included in screening phase four.

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Articles identified as eligible by both the primary reviewer and secondary reviewers had their full text reviewed in screening Phase Three (see Appendix C for screening tool). The primary reviewer reviewed the full text article, as well as both secondary reviewers. The three reviewers discussed any disagreement (Liberati, et al., 2009). Where consensus was reached, successful articles were moved onto screening Phase Four (see Appendix D), otherwise known as Data Extraction, and ineligible articles were excluded. Any article for which agreement was not reached regarding eligibility was moved to Data Extraction for a more detailed review. Articles where there was disagreement included tools that did not directly measure transition readiness and those that were poorly described or discussed questionnaires.

Data Extraction Process

The primary and secondary reviewers extracted data from the selected articles as per the data extraction tool developed for this review (see Appendix D). The following data was extracted from each article and recorded in REDCap: first author, country of origin, original language, and year of publication, as well as, tool and study population information, including the name of the tool, measure format, theoretical underpinnings, intended respondent, median age, diagnosis, age at transfer, dropouts, and timing of outcome assessment. The data extraction table presented all reported characteristics of the measures. The Cohen criteria was used to evaluate the methodological quality of the tools (Cohen, La Greca, et al., 2006).

Synthesis of Data

The primary author tabled the extracted data (see Appendix D for data extraction tool). This table represented a synthesis of measures found in the selected articles. The primary author separated the tools by disease-specific and disease-neutral. Specific data fields included: the name of the tool; the original language; country of origin; target population; measure concepts;

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number of items; who completed the survey; and Cohen Criteria (Cohen, La Greca, et al. 2006) (Table 1). The Cohen Criteria served as a tool for researchers to evaluate the overall evidence supporting the psychometric testing of the transition readiness measures included in the review. Measures were classified as per three categories, “well-established assessment”, “approaching well-established assessment”, and “promising assessment”.

Table 1

Criteria for Evidence-Based Assessments

Category	Criteria
Well-established assessment	<p>The measure must have been presented in at least two peer-reviewed articles by different investigators or investigatory teams</p> <p>Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request)</p> <p>Detailed (e.g., statistics presented) information indicating good validity and reliability in at least one peer-reviewed article</p>
Approaching well-established assessment	<p>The measure must have been presented in at least two peer-reviewed articles, which might be by the same investigator or investigatory team</p> <p>Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request)</p> <p>Validity and reliability information presented in either vague terms (e.g., no statistics presented) or moderate values</p>
Promising assessment	<p>The measure must have been presented in at least one peer-reviewed article</p> <p>Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request)</p> <p>Validity and reliability information presented in either vague terms (e.g., no statistics presented) or moderate values</p>

CHAPTER 4 - RESULTS

Chapter 4 provides the results of this systematic review, including the study selection, characteristics of study participants, and characteristics and methodological quality of the identified transition readiness measures. Please refer to Appendix E for the PRISMA flow diagram for this review. This diagram summarizes the numbers of records identified in each screening phase, duplicates removed, and the final number of articles included in this review. A discussion of the systematic review results is detailed in this chapter.

Study Selection

A total of 1933 articles were identified from the first electronic searches completed in February 2017 (F17). A total of 1851 articles were identified from the second electronic searches completed in January 2018 (J18). A total of 703 duplicates were removed during the initial F17 search, and 1391 from the J18 search. Of the remaining 1230 articles identified in the F17 search, 1178 were excluded during Phase One and Two screening, and 52 moved onto full-text screening. After full-text screening, 30 articles were selected for data extraction. From the 467 articles found in the J18 search, 439 were excluded in screening Phase One and Two, and 28 moved onto full-text screening. From the 28, a total of 18 were selected for data extraction.

A total of 48 articles remained for inclusion in this systematic review; of these, 19 tools were identified. Eight studies involved parents; of the eight, the STARx, TRI, and RTQ had AYA and caregiver/parent parallel versions; there were no measures completed by a healthcare provider (e.g. answered from the healthcare provider's perspective). Ten tools were disease-specific and nine were disease-neutral. However, many of the disease-neutral tools were used with disease-specific populations.

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Three tools originated in Canada that have been utilized in other countries such as Turkey and Japan. Fourteen were developed in the United States, and have been studied in countries such as Canada, Mexico, Brazil, Argentina, and Turkey. The remaining two tools originated in Taiwan and The Netherlands. Of the 19 tools, one was administered by a healthcare provider, the UNC TRxANSITION; while the other 18 were self-report. Twelve used a Likert-scale format, five had a questionnaire format, and two were checklists.

Characteristics of Study Participants

All the articles involved both male and female AYAs diagnosed with a chronic condition; including Type 1 diabetes, congenital heart disease, heart transplantation, muscular dystrophy, cystic fibrosis, sickle cell disease, chronic kidney disease, inflammatory bowel disease, systemic lupus erythematosus, hypertension, lung disease, and cancer. Please refer to Table 2 for detailed information about the diagnosis included in each article. Johnson et al. (2015) reported transition readiness data in the youngest population; children six to 16 years were included with a total of 16 conditions reported, the most common being cerebral palsy and diabetes mellitus. In the remaining articles, participants ranged in age from 11 to 26, with sample sizes ranging from 12 to 1355. Six studies reported the patient's age at transfer, ranging from 17 to 22, and 12 reported the age of diagnosis, ranging from birth to 17. However, it may be implied that age of diagnosis for some conditions was around birth or in infancy, for example, congenital heart disease, cystic fibrosis and sickle cell disease.

Transition readiness was measured by parents as well as AYAs in six studies. Speller-Brown et al. (2015) and Gumidyala et al. (2018) had parents and AYAs fill out parallel versions of the RTQ; similarly, Benson et al. (2018) and Nazareth et al. (2017) asked patients and caregivers to fill out parallel versions of the STARx and STARx-P. Eluri et al. (2017) utilized the

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STARx as well, however, the article is not clear as to whether the STARx or STARx-P was utilized with the parents. Schwartz, Hamilton, et al. (2017) discussed the development of the TRI item pool, which involves a parallel parent version; both tools are still in the early stages of validation and development. Measures from the parental perspective are crucial. There is an ever-changing, balance between adolescent healthcare responsibility and parental involvement during the transition process (Benson et al., 2018; Gilleland et al., 2012; Schwartz, Hamilton et al., 2017). Research by Benson et al. (2018) recognized that parents incorrectly perceive their AYA's feelings of transition and comfort level with their healthcare providers. This research reinforces the need to engage AYAs and their parents and caregivers at an early age and throughout the transition process. AYAs should aim to slowly increase their amounts of healthcare responsibility, as their parents and or caregivers become less involved.

Characteristics of Transition Readiness Measures

The following section provides an overview of the 19 tools identified in the review. The tools are organized alphabetically, with tools without titles at the end. Three of the 19 tools, TRAQ, RTQ, and UNC TRxANSITION, were reported in the previously published systematic reviews.

Adolescent Assessment of Preparation for Transition (ADAPT)

Sawicki, Garvey, Toomey, Williams, Chen, et al. (2015) developed and validated the disease-neutral Adolescent Assessment of Preparation for Transition (ADAPT), a 26-item mailed survey designed for completion by 16 to 17-year-old adolescents with a chronic health condition. The tool was reported in two articles in this review. The tool measures the quality of healthcare transition preparation experiences reported by adolescents and aims to provide practitioners with targets for improvement in adolescent transitional care. Sawicki, Garvey, Toomey, Williams,

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Hargraves, et al., (2017) utilized ADAPT in a more recent study with 575 respondents, looking for differences in ADAPT scores based on clinical and demographic characteristics. Sawicki, Garvey, Toomey, Williams, Hargraves, et al., (2017) found scores in all domains reflected deficiencies in transition preparation; there were no significant differences in sex, type of chronic condition, or insurance plan. Limitations included the cross-sectional designs and low response rate. The tool was not available online.

The Adolescent Autonomy Checklist (SCD-AAC)

Abel et al. (2015) adapted the self-report Adolescent Autonomy Checklist (AAC) for the sickle cell population. This unvalidated, disease-specific tool contains 12 categories listing a total of 100 items for adolescents to gain a better understanding of their ability to perform everyday tasks. The tool was reported in one article in this review. The tool was administered to 122 patients, aged 13 to 21 years, during routine clinic visits. The category of greatest need was living arrangements with 38.5% choosing “needs practice.” Researchers found there was a significant difference in healthcare skills based on age and overall, the needs in most categories decreased as the age increased. Limitations of this study included the cross-sectional design and that the data was collected from a single center. The check list was not available online, and only the categories were discussed in the article.

Congenital Heart Disease (CHD) Transition Readiness Assessment

Uzark et al. (2015) developed and validated the Congenital Heart Disease (CHD) Transition Readiness Assessment. Uzark incorporated and modified the University of North Carolina (UNC) STAR_X questionnaire, as well as the TR_XANSITION scale; the measure was developed to be administered online via an e-tablet. The tool was reported in one article in this review. This validation study had a sample size of 164, with patients ranging from 13 to 25.5,

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mean age of 18.1. Uzark found there was decreased self-efficacy and self-management skills in AYAs with CHD, and this correlated with transition knowledge deficits. Limitations of this study included the cross-sectional design and that data was only collected from one center limiting generalizability. Strengths of this measure are that it is administered online and it is the only measure in this review where the number of items differs based on the participant's gender and medication history. After contacting the researcher on March 21, 2018, a copy of the online e-tablet version of both the pediatric and parent tool were emailed for viewing. In addition, as per the email communication with Uzark on March 21, 2018, this measure is undergoing further validation and psychometric testing.

Healthcare Needs Scale for Youth with Congenital Heart Disease (HNS-CHD)

Chen, Ho, Su, Wang, Chung, and Lee (2018) developed the Healthcare Needs Scale for Youth with Congenital Heart Disease (HNS-CHD) to improve the transition for patients with congenital heart disease surviving into adulthood. This disease-specific, self-report tool includes 25 items divided into three dimensions: health management; health policy; and individual and interpersonal relationships. The tool was reported in one article in this review. Five hundred participants, ranging in age from 15 to 24, took part in the study. It has had initial psychometric testing completed, and met the requirements in terms of construct, concurrent, predictive, and known group validity and internal consistency reliability. However, results are not generalizable due to the specific Taiwanese population recruited. The tool was not easy to locate online, however, an example of the questions was available in the article. A limitation of this study was the cross-sectional design.

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ON TRAC Framework

The ON TRAC Questionnaire for adolescents 12 to 19 years of age was revised and psychometrically evaluated (Moynihan et al., 2015). The tool was reported in two articles in this review. The revised questionnaire included the six transition indicators, had 26 questions and was divided into two domains, knowledge scale and behaviour index. Scoring was based on a four-point Likert scale, strongly agree to strongly disagree, and a five-point ordinal scale, never to always, and is appropriate for youth aged 12 and up. Gravelle, Paone, Davidson, & Chilvers (2015) utilized Moynihan's research to develop and test a Cystic Fibrosis Readiness to Graduate Questionnaire as a final quality improvement intervention for the Multidimensional Cystic Fibrosis Transition Program for patients 16 to 18 years. The goal of the tool was to measure youth perceptions of readiness to transfer to the adult cystic fibrosis healthcare setting; providing adult practitioners a better idea of where the adolescent required attention. Gravelle's tool has not been validated. In contrast to other researchers, Moynihan et al. (2015) proposes reconsidering having a standard age for when transition should occur and looking more closely at health and self-management behaviours. British Columbia Children's hospital has an easily accessible ON TRAC website, <http://ontracbc.ca/>, and Moynihan et al. (2015) featured an overview of the tool in their research article.

On Your Own Feet Transfer Experience Scale (OYOF-TES)

Van Staa and Sattoe (2014) developed the validated, disease-neutral On Your Own Feet Transfer Experience Scale (OYOF-TES) which was based on previous research and qualitative studies. The tool was reported in one article in this review. The tool is for AYAs aged 18 to 25, focuses on experiences with the transfer process and consists of 18 items rated on a five-point Likert scale. The questions are about specific experiences, which allow healthcare practitioners

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to target specific interventions for AYAs. Strengths of this article include the longitudinal design and large field study sample of 1001. However, only 606 out of 1001 participants returned the survey, giving the survey a high non-response rate according to the researcher. Van Staa et al. found positive transfer experience was predicted by good alignment and collaboration between pediatric and adult services. The scale was not available online.

Responsibility and Familiarity with Illness Survey (REFILS)

Annunziato, Bucuvalas, et al. (2018) utilized the disease-neutral Responsibility and Familiarity with Illness Survey (REFILS) tool with a large group of liver transplant patients and their parents. The tool was reported in one article in this review. The REFILS tool measures self-management when patients transition from pediatric care to adult care. Participants ranged from 9 to 17 years of age, with a large sample size of 214 patients and 395 parents. The study further validated the tool, reducing the number of items from 22 to 13. The tool focuses on two domains, perceived knowledge about the illness and responsibility for medical management. Limitations of the tool in this study include the self-report model, and the very specific patient population that was recruited. Annunziato, Bucuvalas, et al. (2018) discovered that patients who reported they are in control were more likely to have negative outcomes. A higher REFILS score, which correlates with an AYA having a higher level of management, was consistently correlated with worse adherence and higher organ rejection. Annunziato, Bucuvalas, et al. (2018) emphasize that the timing of teaching is crucial in respect to development and psychosocial maturity. Annunziato, Bucuvalas, et al. (2018) recommend healthcare providers determine, with empirical support, how best to transition the responsibilities from the parent to the adolescent. This should be based on the individual needs and abilities of the AYA and their parent/caregiver. The REFILS tool was not found online.

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Readiness to Transition Questionnaire (RTQ)

The RTQ is a self-report disease-neutral measure of transition readiness. The tool was reported in three articles in this review. In addition, it was reported in Zhang and her colleagues and Schwartz and her colleagues previously published systematic reviews. The RTQ has a parallel parent version and is utilized by researchers to measure patient and parent report of transition readiness. Items range from 22 to 26 questions and are ranked on a Likert-scale with scores ranging from 10 to 40 for overall adolescent responsibility and parent involvement, and 2 to 8 for overall transition readiness. In this review the number of participants ranged from 60 to 163, aged 12 to 20. Researchers found AYAs showed deficits in responsibility for their disease management. Strengths of the RTQ include the parallel parent version. The parallel versions give healthcare providers a tool to quickly screen both AYAs and their parents for transition readiness and identify areas where education and support is needed. Limitations of these studies included the cross-sectional design and that data was only collected from one site making generalizability difficult. Gilleland et al. (2012), the original author of the tool, has an example of the AYA RTQ in his article; the parent version is not available online.

Sickle Cell Transition Intervention Program Skills Checklists

Sobota et al. (2014) developed the sickle cell Transition Intervention Program Skills Checklists. The tool was reported in one article in this review. This self-administered measure consists of five knowledge skill sets and three psychological checklists. This tool has not been validated and was used with a convenience sample of 33 AYAs, 18 to 22 years with Sickle Cell disease. Sobota et al. found AYAs reported low levels of understanding about health insurance. They also reported limited social supports to talk to about their chronic disease. Limitations of

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this study include the cross-sectional design and small sample size. Examples of the tool are found in the research article.

STARx

Like the TRxANSITION, Ferris, Cohen, et al. (2015) developed the Self-Management and Transition to Adulthood with Rx Treatment (STAR_x) questionnaire to collect or generate information on self-management and healthcare transition (HCT) skills. This is a disease-neutral, self-report tool developed to be administered to AYAs with chronic conditions. The STAR_x was reported in six articles in this review. This validated tool has 18 questions and takes about 3 minutes to complete. It may be used with adolescents as young as 12 years old, with a focus on utilizing a patient score to guide education and intervention so the youth may gain the given skill before transition (Cohen, Hooper, et al., 2015; Ferris, Cohen, et al., 2015). In addition, there is a parallel parent version, STAR_x-P, to assist healthcare providers by assessing a parental version of AYA transition readiness, simultaneously with the adolescent (Nazareth et al., 2017). Like other articles in this review, Ferris, Cohen, et al. (2015) found transition readiness is correlated with age, and the STAR_x may be used to measure improvements in transition readiness following the implementations of interventions. The STAR_x is available online. The publications in this review that utilized the STAR_x are limited to cross-sectional designs.

Transition Intervention Program- Readiness for Transition (TIP-RFT)

Treadwell et al., (2016a) developed the validated Transition Intervention Program-Readiness for Transition (TIP-RFT) assessment for AYAs with sickle cell disease. The 22-item tool was validated with AYAs aged 14 to 26 and has been used successfully at two outpatient sickle cell centers. The TIP-RFT was reported in two articles in this review. Treadwell et al., (2016b) utilized the tool to confirm that higher self-efficacy was associated with better transition

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readiness. Limitations of the article include the cross-sectional designs, and convenience sampling of 113 participants. In addition, some participants filled out the survey in a group setting and did not answer every question. The TIP-RFT was not found online.

TRANSITION-Q

Klassen, Grant, et al. (2015) developed the TRANSITION-Q for adolescents 12 to 18 with chronic health conditions. Klassen, Grant, et al. (2015) used Rasch Measurement Theory (RMT) analysis to examine reliability and validity. The tool is psychometrically sound and was translated into Turkish and used by Ekim, Kolay, and Ocakci (2018) to successfully measure transition readiness in adolescents 12 to 18 years of age with chronic heart disease. The TRANSITION-Q was reported in two articles in this review. The tool may be used to track, measure and set developmentally appropriate goals for self-management skills needed to transition to adult care (Klassen, Grant, et al., 2015; Nguyen et al., 2016). Klassen, Grant, et al. (2015) and Ekim et al. (2018) administered the tool to AYAs 12 to 18, with sample sizes ranging from 113 to 337. Both researchers found self-management skills and overall transition readiness increased significantly with age. Limitations of the studies include the cross-sectional design and that the data was collected from a single institute. Both researchers have examples of the tool in their articles for readers to view.

Transition Readiness Assessment Questionnaire (TRAQ)

The TRAQ was reported in 17 of the 48 articles, both methodological studies and empirical studies. In addition, it was previously reported in all three of the previously published systematic reviews. Developed by Sawicki, Lukens-Bull, et al. (2009), the TRAQ is one of the few available validated, patient-reported, disease-neutral transition readiness tools (Zhang et al., 2014). This tool adopted the framework of the Stages of Change Model, which focused on the influence of

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social and biological variables on the AYAs behaviour and decision-making skills (Kiziler, Yildiz, & Eren, 2017; Sawicki, Lukens-Bull, et al., 2009). The tool was used with both disease-specific and disease-neutral populations. The TRAQ 4.1 was used in nine studies, and the newly developed TRAQ 5.0, was utilized in eight.

Beal et al. (2016) utilized the TRAQ 5.0 as well as the Readiness to Transition Questionnaire (RTQ) (Gilleland et al., 2012). The TRAQ measures transition readiness of youth, 16 to 26, with chronic conditions under two domains: (1) self-advocacy (e.g. communication and use of resources within the community and school); and (2) chronic disease self-management (e.g. scheduling medical appointments, asking questions of healthcare providers, filling prescriptions) (Schwartz, Tuchman, et al., 2011; Stinson et al., 2014; Wood et al., 2014). TRAQ 4.1 has been previously validated with 461 youth ages 16 to 26 across 2 studies (Beal et al., 2016; Schwartz, Tuchman, et al., 2011) and a wide variety of complex health conditions. These included Type 1 diabetes, spina bifida, cerebral palsy, cystic fibrosis, sickle cell disease, seizure disorders, and autism (Schwartz, Tuchman, et al., 2011). Item responses are on a 5-point Likert type scale ranging from 1 (no, I don't know how) to 5 (yes, I always do this when I need to). The TRAQ is for AYAs 16 to 26 years, and researchers continue to be unable to reproduce the measure's factor structure with younger populations under 16 (Carlsen et al., 2017; Klassen, Grant, et al., 2015; Moynihan et al., 2015).

Although TRAQ 4.1 and 5.0 have not previously been validated in young people without chronic conditions, the 20 items included on TRAQ 5.0 are all relevant to youth who do not carry a chronic diagnosis (Beal et al., 2016). The articles included in this review had sample sizes ranging from 18 to 526, with AYAs 11 to 26 years. The TRAQ 5.0 has recently been translated and validated in Brazilian Portuguese (Anelli, Len, Terreri, Russo, & Reiff, , 2018),

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Argentinian Spanish (Gonzalez et al., 2017) and Turkish (Kiziler, Yildiz, & Eren, 2017). The TRAQ 5.0 is easily accessible online <https://www.etsu.edu/com/pediatrics/traq/>. Jensen et al., (2017) found that nearly half of participants reported not discussing transition with their provider. Of the longitudinal studies, researchers found low baseline TRAQ scores, with an improvement following the implementation of process or program for transitioning patients from pediatric care to adult care (Huang et al., 2014; Little, Odiaga, & Minutti 2017; Mackie, Islam, et al., 2014; Okumura et al., 2014; Seeley & Lindeke, 2017).

Transition Readiness Inventory Item Pool (TRI)

Schwartz, Hamilton, et al. (2017) developed the TRI-Item Pool based on the Social - ecological Model of Adolescent and young adult Readiness for Transition (SMART). The validated self-report tool was reported in one article in this review. It is still being developed and represents the first multi-informant transition readiness item pool that comprehensively measures pre-existing factors and modifiable variables. The tool has a parallel parent version to the AYA's, and tool development was informed by multiple stakeholders which supports its content validity and ability to measure the concepts intended. This tool is disease-specific and therefore may not be generalizable for other medical conditions. This tool is the first to use Patient Reported Outcomes Information System endorsed methods for development. Further research and development of the TRI-item pool is in progress. The TRI-item pool is still being developed and therefore is not available online.

Transition Scales

Klassen, Rosenberg, et al. (2015) developed disease-specific, validated Transition Scales to measure cancer patient's readiness for transition to long term follow up care as adults for patients 15 to 26 years of age. The tool was reported in two articles in this review. Klassen, Rosenberg, et

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al. (2015) developed three scales that measure cancer worry, self-management skills and expectations about adult long term follow up care, with a total of 34 questions. Ishida, Tezuka, Hayashi, and Inoue (2016) translated the validated scales into Japanese, and surveyed 108 AYAs, 15 to 26 years. Results found a significantly higher number of Japanese childhood cancer survivors preferred to visit the same doctor for long-term care as adults. Limitations of both studies include the cross-sectional design. A limitation is that Klassen, Rosenberg, et al. (2015) collected data from only three of the 16 pediatric oncology centers in Canada, making the results difficult to generalize. Klassen, Rosenberg, et al. (2015) provided an example of the scales for readers to view.

UNC TRxANSITION

The theoretically informed, validated UNC TRxANSITION Scale was developed by Ferris, Harward, et al. (2012). This disease-neutral tool was reported in three articles in this review. In addition, it was reported in all three of the previously published systematic reviews. It has been translated and validated in Spanish (Cantu-Quintanilla et al., 2015), and administered in countries such as India (Javalkar, Williamson, Vaidya, Vaidya, & Ferris, 2016). The tool takes between 7 and 8 minutes to complete, has a standardized scoring system from 0 to 10, and may be administered to adolescents 12 to 20. The UNC TRxANSITION was utilized in four articles and is the only measure administered by a healthcare provider as opposed to being completed by the adolescent independently. Participants 12 to 31 years took part with sample sizes ranging from 41 to 511. Javalkar, Johnson, et al. (2016) recognized or identified age and insurance plan coverage as important predictors of the AYAs transition readiness. A limitation of the measure is the cross-sectional design of the study. The UNC TRxANSITION is available online; interested researchers must fill out a form to receive a copy of the tool.

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Tools Without Titles

Polfuss, Babler, Bush and Sawin (2015) developed a survey to measure family, adolescent and parent perceptions of a variety of diabetes related transition topics. The survey was reported in one article. It was designed to focus on the topics covered in the transition classes and Moving On binder offered to the adolescents. The binder included educational material put together by the diabetes team, such as driving, nutrition, exercise and physical activity and sexual health. The Individual and Self-Management Theory, developed by Ryan and Sawin (2009), was used to guide this study and the development of the diabetes transition program. Polfuss et al. (2015) found adolescents had a slightly higher level of confidence in themselves than their parents did. Recognizing what parents and adolescents believe is important and targeting intervention based on both family and adolescent perceptions has the potential to lead to optimal and successful outcomes. Limitations of this tool and article include the lack of a title, the cross-sectional design and the small sample size. The survey was not found online, however, there was an example of survey questions in the article.

Du Plessis, Culnane, Peters and d'Udekem (2017) utilized a previously developed disease-neutral, unvalidated and unnamed tool. The tool was reported in one article in this review. The researchers utilized the tool with a small group of adolescents with complex congenital heart disease who had undergone a series of operations that culminate in the Fontan procedure and their parents. The three-page questionnaire was previously developed as an in-house program evaluation tool by the Royal Children's Hospital in Melbourne Australia. Their sample size was small, 17 AYAs aged 15 to 18, and 15 parents. Du Plessis et al. (2017) found adolescents had poor knowledge about Fontan Circulation and a poor understanding of their medications and chronic disease management. Limitations of the study included the small sample size, the lack of

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psychometric evaluation for the tool, and that the tool does not have age criteria. The tool is not available on line.

Summary

A total of 19 tools have been identified and briefly described above. In summary, eleven tools were disease- specific, meaning they were developed for a specific chronic illness, and eight were disease-neutral, meaning they could be utilized by an adolescent or young adult with any chronic illness. Both categories of tools have advantages for research and clinical application.

Methodological Quality of Transition Readiness Measures Studies

To test the quality and overall evidence supporting the psychometric testing of the transition readiness measures the Cohen Criteria was used (Cohen, La Greca, et al., 2006). The Cohen criteria provide a three-level ranking system designed to critique and analyze measures (Table 1). The Cohen criteria was chosen for this review because of the straightforward application of the criteria.

In this review, seven of the 19 tools achieved a ranking of “well-established assessment” (Table 2). Five tools achieved a ranking of “approaching well-established assessment”, and four achieved a ranking of “promising assessment”. The three remaining measures did not achieve a ranking in any of the categories, indicating that their psychometric qualities were inadequately reported or not reported at all.

CHAPTER 5 - DISCUSSION

Over the past 10 years the literature has been saturated with the development and validation of new and existing transition readiness measures. This study aimed to systematically review peer reviewed articles on transition readiness measures and tools for AYAs with chronic illnesses and the methodological quality of each measure and tool. This study systematically reviewed and synthesized the literature since 2014, when Stinson et al. (2014), Zhang et al. (2014) and Schwartz, Daniel, et al. (2014) completed simultaneous systematic reviews of transition readiness measures and tools. Compared to previous systematic reviews, the number of articles included in this review was significantly higher. Stinson et al. (2014) had 14 in their studies, and Zhang et al. (2014) and Schwartz, Daniel, et al. (2014) each had 10 studies. The inclusion criterion was similar across all four systematic reviews. In addition, like previous reviews, both validated and unvalidated measures were included. Within the 48 articles, of the 19 identified tools, ten were validated and six were not validated. Researchers reported initial validation of three tools and discussed future implications to include further validity and reliability studies (Table 2). The large number of articles (n=48) in this review highlights the increasing attention on the study of transition readiness measures, both new and previously developed. There is recognition that measures are still in the infancy stage and measures that have been rigorously tested with multiple patient populations and large sample sizes.

Methodological Quality

Despite multiple national clinical guidelines for healthcare transition, deficiencies continue to be found in the quality of transition readiness and transition preparation (Sawicki, Garvey, Toomey, Williams, Hargraves, et al., 2017). This review identified 19 measures of transition readiness used in studies published in peer-reviewed journals. Seven of the 19 measures (37%)

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achieved a status of “well-established assessment” according to the Cohen criteria (Cohen, La Greca, et al., 2006). This indicates that the measures were published in at least two peer-reviewed journals, were easily accessible, either the measure, manual or both, and reported detailed information about validity and reliability. Five tools were classified as “approaching well-established”; indicating the measures were published in at least two peer-reviewed journals by the same investigatory team; the researchers provided sufficient detail about the measure for replication and evaluation; and the tools validity and reliability was vaguely described. Finally, four tools were classified as “promising assessment”; indicating the measures were published in at least one peer reviewed journal; validity and reliability were presented in vague terms or not presented at all; and there were limited details about the measure to allow for evaluation and replication. In addition, two measures in this current review did not have titles and six measures were only published in one peer-reviewed journal. Three measures did not meet the Cohen criteria.

This represents an improvement since the Stinson et al., (2014) systematic review, where no tools were classified as “well-established” and six out of 7 tools (86%) received a ranking of “promising assessments”. In the other systematic reviews by Zhang and her colleagues and Schwartz and her colleagues, methodological quality was not assessed. Researchers agree a successful transition process requires a standard approach in assessing and facilitating the maturity and self-management of an adolescent; however, there continues to be a lack of structured transition programs and operational definitions (AAP & AAFP, 2011; Coyne, Sheehan, Heery, & While, 2017).

Theoretical Foundation

Schwartz, Daniel, et al., (2014) emphasized the importance of grounding measures in theory to support the validity of the new measures. However, a minority of the measures (Got Transition, TRAQ 4.1 and 5.0, TRI-item pool, and AM I ON TRAC) were informed by theory, frameworks and models, including the ON-TRAC framework, individual and self-management theory (ISMT), stages of change model, and SMART. In addition, many tools do not capture socio-ecological factors that are theoretically important for transition readiness (Schwartz, Hamilton, et al., 2017; Szalda et al., 2017). The majority of the measures in this review focused on disease knowledge, disease self-management, medication management, and provider communication. Researchers agree measuring patient experience, as well as self-management and self-advocacy skills is needed. By measuring patient experience, healthcare providers will be able to evaluate and compare the quality of the transition preparation among clinical programs or larger health systems (Sawicki, Garvey, Toomey, Williams, Chen, et al., 2015; Sawicki, Garvey, Toomey, Williams, Hargraves, et al., 2017). Future research must focus on psychological characteristics affecting life-long successful self-management regardless of age, while also including the provider and family perspective (Carlsen et al., 2017; Trivedi, Holl, Hanauer, & Keefer, 2016).

Measurement of Transition Readiness over Time

As part of developing more reliable evidence-based transition programs and transition processes, guidelines provided by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and American College of Physicians-American Society of Internal Medicine (ACP-ASIM) (2002), recommended that providers regularly assess transition readiness using an objective measure (Jensen et al., 2017). However, of the 48 articles

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included in this review, only seven had a longitudinal design. This was highlighted as a need for future tool development in the previously published systematic reviews; however, this continues to be an area for improvement. In this review the following, longitudinal measures were identified; TRAQ and OYOF-TES. Transition is not a one-time event; a thorough transition readiness measure with a longitudinal design will be useful in personalizing the transition process for AYAs and their healthcare team (Seeley & Lindeke, 2017; Stinson et al., 2014). Researchers agree, the transition process may take many years (Little et al., 2017; Seeley & Lindeke, 2017). Having the ability to routinely assess transition readiness overtime will lead to the introduction of interventions specific to an AYA's individual needs (AAP & AAFP, 2011; Little et al., 2017; Wood et al., 2014).

Age, Transition Readiness and Transfer

Researchers agree transition interventions should begin at an early age (Jensen et al., 2017; Klassen, Rosenberg, et al., 2015; Little et al., 2017; Seeley & Lindeke, 2017). Previous studies have consistently demonstrated that the only predictor of transition readiness is the non-modifiable characteristics of age (Carlsen et al., 2017; Johnson et al., 2015). Increasing age correlates with increasing transition related knowledge (Beal et al., 2016; Gumidyala et al., 2018; Mackie et al., 2016; Moynihan et al., 2015; Speller-Brown et al., 2015); however, chronological age may not be the best indicator of transition readiness (Little et al., 2017; Moynihan et al., 2015). Research by Annunziato, Freiburger, et al. (2014) and Hart et al. (2016) recognized age should not define readiness for transition; instead, it should develop over time as the adolescent achieves targeted psychosocial, educational and medical independence. It can take several years for patients to gradually assume responsibility for chronic disease management (Little et al., 2017). Assessing psychosocial maturity gives healthcare providers the ability to be flexible and

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client centered throughout the transition period. Flexibility in achieving transition readiness is possible in all cases on the age to begin introduction; however, may be limited on the upper age because of funding restrictions for some healthcare providers where funding expires once the AYA reaches 18. Smooth transition involves individualization and ongoing assessments of transition readiness. Researchers agree transition planning should begin around the age of 12 to 14 years, allowing AYAs time to master skills necessary to responsibly manage their own healthcare (AAP & AAFP, 2011; Gumidyala et al., 2018; Sawicki, Garvey, Toomey, Williams, Chen, et al., 2015; Seeley & Lindeke, 2017). To meet the needs of AYAs and promote successful transitions, measures of transition readiness need to be longitudinal in design. Previous systematic reviews did not comment specifically on age.

Engagement of Multiple Stakeholders

Planned strategies should begin engaging an AYA before the expected transition period and involve all members of the pediatric healthcare team for consistency. AYAs and their caregivers or parents should be engaged in the preparation for transition services beginning around the age of 12 to 14 years (Benson et al., 2018). Previous systematic reviews recommended assessing transition readiness from multiple perspectives yet most measures lack the view of the lack of the parents or healthcare providers (Schwartz, Daniel, et al., 2014; Stinson et al., 2014). Only eight of the 48 studies utilized parents in the measures of transition readiness. In this review, two tools had parallel parent or caregiver versions (STARx-P, RTQ), and no tools had healthcare provider versions. Routine assessment of transition readiness with patient, and provider recognition of transition knowledge and behaviours deficits will prompt interventions to promote successful transition to adulthood and maximize lifelong physical and psychosocial functioning (Sobota et al., 2014; Uzark et al., 2015).

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Patients' readiness for transition needs to be accurately and regularly assessed by applying validated measurement tools (Zhou, Roberts, Dhaliwal, & Della, 2016). The priority for healthcare providers for both pediatric and adult services is to develop a universally structured process and evidence-based transition program, utilizing validated universal tools, which must be user-friendly to all patients and not disease specific (Coyne et al., 2017; Zhou et al., 2016). An improved transition process that educates AYAs involves parental perspectives and engages the healthcare provider has the potential to improve quality of life and decrease the burden on the healthcare system (Fenton et al., 2015; Klostermann, McAlpin, Wine, Goodman, & Kroeker, 2018).

Transition Readiness Assessment Questionnaire (TRAQ)

The TRAQ was previously recommended or identified as the best validated tool (Jensen et al., 2017; Zhang et al., 2014). Based on this systematic review, it is evident that the TRAQ, as a disease-neutral tool, remains the best validated tool. The tool has been utilized with multiple chronic disease populations, in both disease-specific and disease-neutral environments. The TRAQ is easy to administer, short to fill out, and easily available online to download and utilize. It has been implemented in countries around the world, such as Canada, the United States, Brazil, Argentina, and Turkey. Use of the TRAQ has successfully shown positive longitudinal transition readiness scores over 6 years with AYAs with 16 different chronic diseases (Johnson et al., 2015). The TRAQ has been translated and validated to Brazilian Portuguese, Argentinian Spanish, and Turkish. The TRAQ has not been validated in adolescents less than 16 (Stewart et al., 2017).

Limitations

This review systematically identified and evaluated the current measures of transition readiness for AYAs transitioning to adult care. The literature search included only articles published in peer reviewed journals; therefore, measures nearing completion or awaiting publication were not included. A systematic review is a form of knowledge synthesis. It summarises the results of healthcare studies and provides an overview of the effectiveness of healthcare interventions. Researchers can make conclusions about the evidence and inform recommendations for healthcare (Green & McDonald, 2005). There is currently no “gold standard” measure of transition readiness; therefore, the researcher anticipated the standard validity of transition readiness tools as difficult to establish (Zhang et al., 2014). This review is proof of the growing interest in measures of transition readiness. In addition, only English manuscripts were included, and many of the studies originated in Canada or the United States. Due to the country of origin, many of the measures had questions directed to those living in Canada or the United States, such as the TRAQ’s questions about health insurance. These measures may not be appropriate in other countries.

Conclusion

In conclusion, this review was timely given the proliferation of published articles in the field of transition. In the short time period, four years, 48 articles were included, representing 19 tools. This represents a large volume increase in published articles related to the measurement of transition readiness. An additional strength of this review is that it demonstrated an advancement in the field of measurement by utilizing the Cohen criteria, which is consistent with the way that Stinson et al. (2014) determined methodological quality in her systematic review. Subsequent

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systematic reviews of transition readiness should utilize the Cohen criteria for continued consistency.

The TRAQ remained the best validated measure of transition readiness. Utilized in 17 of the 48 articles, researchers agreed, it remains the most reliable, valid, and widely used tool. The TRAQ's disease-neutral design has allowed researchers from countries across the world to utilize the tool, in both English, Argentinian Spanish, Turkish, and Brazilian Portuguese, with little modification needed. Future research should focus on longitudinal research studies and the validation of the tool with patient populations under 16 (Stewart et al., 2017).

Surgical and medical advancements have improved the likelihood of chronically ill children surviving into adulthood. Even after the release of the CAPHC Guidelines in June 2016 and the ongoing policy development and research by the AAP and AAFP (2011), there continues to be a slow movement towards achieving a “gold standard” measure of transition readiness and standardized approach for healthcare providers. Transfer from the pediatric to the adult healthcare system can be challenging to the families, clients as well as the teams of healthcare providers. Without adequate support, many AYAs are unable to transfer to adult healthcare successfully. Transition is a crucial time period; many AYAs lack important self-management and healthcare utilization skills and are inadequately equipped to move to adult care (Jensen et al., 2017). It was demonstrated in this review that there are few theory informed measures of transition readiness. This was similar to findings of previous systematic reviews. Clinicians and researchers continue to create their own tools ad hoc instead of utilizing previously validated and well-established measures. Regardless of the chronic condition, without a well-designed transition measure, such as the TRAQ, AYAs are at an increased risk for loss to follow-up during the challenging transfer period (Foster et al., 2017; Gurvitz et al., 2013; Ramos, Hoffmann,

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Albrecht, Klotsche, Zink, & Minden, 2017; Yeung et al., 2008). Clinicians have the potential to feel more confident beginning the transfer process with adolescents if they have access to appropriate transition readiness measures. A thorough readiness assessment can be useful in personalizing the transition process for each individual adolescent.

MEASURES OF TRANSITION READINESS

References

- Abel, R. A., Cho, E., Chadwick-Mansker, K. R., D'Souza, N., Houston, A. J., & King, A. A. (2015). Brief report-Transition needs of adolescents with sickle cell disease. *American Journal of Occupational Therapy, 69*, 6902350030p1-6902350030p5. doi: 10.5014/ajot.2015.013730
- Agarwal, S., Garvey, K. C., Raymond, J. K., & Schutta, M. H. (2017). Perspectives on care for young adults with Type 1 diabetes transitioning from pediatric to adult health systems: A national survey of pediatric endocrinologists. *Pediatric Diabetes, 18*(7), 524-531. doi: 10.1111/pedi.12436
- American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians-American Society of Internal Medicine (ACP-ASIM) (2002). A consensus statement on health care transition for young adults with special health care needs. *Pediatrics, 110*, 1304-1306. Retrieved from http://pediatrics.aappublications.org/content/pediatrics/110/Supplement_3/1304.full.pdf
- American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 128*(1), 182-200. doi:10.1542/peds.2011-0969
- Anelli, C. G., Len, C. A., Terreri, M. T., Russo, G. C., & Reiff, A. O. (2018). Validation of a Brazilian Portuguese version of the transition readiness assessment questionnaire (TRAQ) in a population of transitional youth with chronic rheumatologic disorders. *Jornal De Pediatria*. doi:10.1016/j.jpmed.2017.12.013
- Annunziato, R. A., Freiberger, D., Martin, K., Helcer, J., Fitzgerald, C., & Lefkowitz, D. S. (2014). An empirically based practice perspective on the transition to adulthood for solid

MEASURES OF TRANSITION READINESS

- organ transplant recipients. *Pediatric Transplantation*, 18(8), 794-802. doi:
10.1111/petr.12359
- Annunziato, R. A., Bucuvalas, J. C., Yin, W., Arnand, R., Alonso, E. M., Mazariegos, G. V., ... & Shemesh, E. (2018). Self-management measurement and prediction of clinical outcomes in pediatric transplant. *The Journal of Pediatrics*, 193, 128-133.
<https://doi.org/10.1016/j.jpeds.2017.09.069>
- Beal, S. J., Riddle, I. K., Kichler, J. C., Duncan, A., Houchen, A., Casnellie, L., ... Corathers, S. D. (2016). The associations of chronic condition type and individual characteristics with transition readiness. *Academic Pediatrics*, 16(7), 660-667. doi:
10.1016/j.acap.2016.06.007
- Benson, N. D., Cunningham, C., Braun, L., Wallace, J., Stewart, K., & Derouin, A. (2018). Transitioning pediatric patients to adult health care: A quality improvement needs assessment. *Journal of Pediatric Health Care*.
<https://doi.org/10.1016/j.pedhc.2017.09.014>
- Berwick, D. M., Nolan, T. W., & Whittington, J. (2017). The triple aim: Care, health, and cost. *Health Affairs*, 27(3), 759-769. doi: 10.1377/hlthaff.27.3.759
- Blum, R. W., Garrell, D., & Hodgman, C. H. (1993). Society for adolescent medicine. Position paper. Transition from child centered to adult health care systems for adolescents with chronic conditions. *Journal of Adolescent Health*, 14, 570-576. doi:
[http://dx.doi.org/10.1016/1054-139X\(93\)90143-D](http://dx.doi.org/10.1016/1054-139X(93)90143-D)
- Canadian Association of Pediatric Health Centres (CAPHC), National Transitions Community of Practice (2016). *A guideline for transition from paediatric to adult health care for youth with special health care needs: A national approach*. Retrieved from

MEASURES OF TRANSITION READINESS

- <http://ken.caphc.org/xwiki/bin/view/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care>
- Cantú-Quintanilla, G., Ferris, M., Otero, A., Gutiérrez-Almaraz, A., Valverde-Rosas, S., Velázquez-Jones, L., ... Medeiros, M. (2015). Validation of the UNC TRANSITION scale™ version 3 among Mexican adolescents with chronic kidney disease. *Journal of Pediatric Nursing, 30*(5), 71-81. doi: <http://dx.doi.org/10.1016/j.pedn.2015.06.011>
- Carlsen, K., Haddad, N., Gordon, J., Phan, B. L., Pittman, N., Benkov, K., ... Keefer, L. (2017). Self-efficacy and resilience are useful predictors of transition readiness scores in adolescents with inflammatory bowel diseases. *Inflammatory Bowel Diseases, 23*(3), 341-346. doi: [10.1097/MIB.0000000000001038](https://doi.org/10.1097/MIB.0000000000001038)
- Chen, C. W., Ho, C. L., Su, W. J., Wang, J. K., Chung, H. T., Lee, P. C., ... & Hwang, B. T. (2018). Initial validation of a healthcare needs scale for youth with congenital heart disease. *Journal of Advanced Nursing, 74*(1), 223-231. doi: [10.1111/jan.13390](https://doi.org/10.1111/jan.13390)
- Clemente, D., Leon, L., Foster, H., Carmona, L., & Minden, K. (2017). Transitional care for rheumatic conditions in Europe: Current clinical practice and available resources. *Pediatric Rheumatology, 15*(1), 49-55. doi: [10.1186/s12969-017-0179-8](https://doi.org/10.1186/s12969-017-0179-8)
- Cohen, L. L., La Greca, A. M., Blount, R. L., Kazak, A. E., Holmbeck, G. N., & Lemanek, K. L. (2006). Introduction to special issue: Evidence-based assessment in pediatric psychology. *Journal of Pediatric Psychology, 33*(9), 911-915. doi:[10.1093/jpepsy/jsj115](https://doi.org/10.1093/jpepsy/jsj115)
- Cohen, S. E., Hooper, S. R., Javalkar, K., Haberman, C., Fenton, N., Lai, H., . . . Ferris, M. (2015). Self-management and transition readiness assessment: Concurrent, predictive and discriminant validation of the STARx questionnaire. *Journal of Pediatric Nursing, 30*(5), 668-676. doi:[10.1016/j.pedn.2015.05.006](https://doi.org/10.1016/j.pedn.2015.05.006)

MEASURES OF TRANSITION READINESS

- Coyne, I., Sheehan, A. M., Heery, E., & While, A. E. (2017). Improving transition to adult healthcare for young people with cystic fibrosis: A systematic review. *Journal of Child Health Care, 21*(3), 312-330. doi:10.1177/1367493517712479
- Davis, A. M., Brown, R. F., Taylor, J. L., Epstein, R. A., & McPheeters, M. L. (2014). Transition care for children with special health care needs. *Pediatrics, 134*(5), 900-908. doi:10.1542/peds.2014-1909
- Devine, K. A., Monaghan, M., & Schwartz, L. A. (2017). Introduction to the special issue on adolescent and young adult health: Why we care, how far we have come, and where we are going. *Journal of Pediatric Psychology, 42*(9), 903-909. doi:10.1093/jpepsy/jsx101
- Dobbels, F., Ruppard, T., De Geest, S., Decorte, A., Damme-Lombaerts, V., & Fine, R. N. (2010). Adherence to the immunosuppressive regimen in pediatric kidney transplant recipients: A systematic review. *Pediatric Transplantation, 14*(5), 603-613. doi:10.1111/j.1399-3046.2010.01299.x
- Du Plessis, K., Culnane, E., Peters, R., & d'Udekem, Y. (2017). Adolescent and parent perspectives prior to involvement in a Fontan transition program. *International Journal of Adolescent Medicine and Health*. doi: 10.1515/ijamh-2017-0021
- Ekim, A., Kolay, M., & Ocakci, A. F. (2018). Readiness for transition from pediatric to adult care for adolescents with chronic heart disease. *Journal for Specialists in Pediatric Nursing, 23*(1), e12199. doi:10.1111/jspn.12199
- Eluri, S., Book, W. M., Kodroff, E., Strobel, M. J., Gebhart, J. H., Jones, P. D.,... Dellon, E. S. (2017). Lack of knowledge and low readiness for health care transition in eosinophilic esophagitis and eosinophilic gastroenteritis. *Journal of Pediatric Gastroenterology and Nutrition, 65*(1), 53-57. doi:10.1097/MPG.0000000000001415

MEASURES OF TRANSITION READINESS

- Fenton, N., Ferris, M., Ko, Z., Javalkar, K., & Hooper, S. R. (2015). The relationship of health care transition readiness to disease-related characteristics, psychosocial factors, and health care outcomes: Preliminary findings in adolescents with chronic kidney disease. *Journal of Pediatric Rehabilitation Medicine, 8*(1), 13-22. doi:10.3233/PRM-150314
- Ferris, M., Cohen, S., Haberman, C., Javalkar, K., Massengill, S., Mahan, J. D., ... Phillips, A. (2015). Self-management and transition readiness assessment: Development, reliability, and factor structure of the STAR x questionnaire. *Journal of Pediatric Nursing, 30*(5), 691-699. doi:10.1016/j.pedn.2015.05.009
- Ferris, M. E., Harward, D. H., Bickford, K., Layton, J. B., Ferris, M. T., Hogan, S. L., ... Hooper, S. R. (2012). A clinical tool to measure the components of health-care transition from pediatric care to adult care: The UNC TRxANSITION scale. *Renal Failure, 34*(6), 744-753. doi:10.3109/0886022X.2012.678171
- Foster, H. E., Minden, K., Clemente, D., Leon, L., McDonagh, J. E., Kamphuis, S., ... Tattersall, R. (2017). EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Annals of the Rheumatic Diseases, 76*(4), 639-646. Retrieved from <https://doi.org/10.1136/annrheumdis-2016-210112>
- Furlan, J. C., Singh, J., Hsieh, J., & Fehlings, M. G. (2011). Methodology of systematic reviews and recommendations. *Journal of Neurotrauma, 28*(8), 1335-1339. doi:10.1089=neu.2009.1146
- Gabriel, P., McManus, M., Rogers, K., & White, P. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *The Journal of Pediatrics, 188*, 263-269. doi:10.1016/j.jpeds.2017.05.066

MEASURES OF TRANSITION READINESS

- Garvey, K. C., Finkelstein, J. A., Laffel, L. M., Ochoa, V., Wolfsdorf, J. I., & Rhodes, E. T. (2013). Transition experiences and health care utilization among young adults with Type 1 diabetes. *Patient Preference and Adherence*, 7, 761-769. doi:10.2147/PPA.S45823
- Gilleland, J., Amaral, S., Mee, L., & Blount, R. (2012). Getting ready to leave: Transition readiness in adolescent kidney transplant recipients. *Journal of Pediatric Psychology*, 37(1), 85-96. doi:10.1093/jpepsy/jsr049
- Gonzalez, F., Roizen, M., Rodríguez Celin, M. L. M., De Cunto, C., Eymann, A., Mato, R., ... & Fano, V. (2017). Validation of the Argentine Spanish version of transition readiness assessment questionnaire for adolescents with chronic conditions. *Archivos argentinos de pediatria*, 115(1), 18-27. doi:10.5546/aap.2017.eng.18
- Grady, K. L., Van't Hof, K., Andrei, A. C., Shankel, T., Chinnock, R., Miyamoto, S., ... & Lefkowitz, D. (2018). Pediatric heart transplantation: Transitioning to adult care (TRANSIT): Baseline findings. *Pediatric Cardiology*, 39(2), 354-364. doi:10.1007/s00246-017-1763-x
- Graham, I. D. (2012). Knowledge synthesis and the Canadian institutes of health research. *Systematic Reviews*, 1(1), 6-7. doi:10.1186/2046-4053-1-6
- Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, 26(2), 91-108. doi:10.1111/j.1471-1842.2009.00848.x
- Gravelle, A. M., Paone, M., Davidson, A. G., & Chilvers, M. A. (2015). Evaluation of a multidimensional cystic fibrosis transition program: A quality improvement initiative. *Journal of Pediatric Nursing*, 30(1), 236-243. doi:10.1016/j.pedn.2014.06.011

MEASURES OF TRANSITION READINESS

- Green, S., & McDonald, S. (2005). Cochrane collaboration: More than systematic reviews? *Internal Medicine Journal*, 35(1), 3-5. doi:10.1111/j.1445-5994.2004.00747.x
- Gumidyala, A. P., Greenley, R. N., Plevinsky, J. M., Poulopoulos, N., Cabrera, J., Lerner, D., . . . Kahn, S. A. (2018). Moving on: Transition readiness in adolescents and young adults with IBD. *Inflammatory Bowel Diseases*, 24(3), 482-489. doi:10.1093/ibd/izx051
- Gurvitz, M., Valente, A. M., Broberg, C., Cook, S., Stout, K., Kay, J., ... Houser, L. (2013). Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). *Journal of the American College of Cardiology*, 61(21), 2180-2184. doi:10.1016/j.jacc.2013.02.048
- Hart, L. C., Pollock, M., Hill, S., & Maslow, G. (2016). Association of transition readiness to intentional self-regulation and hopeful future expectations in youth with illness. *Academic Pediatrics*, 17(4), 450-455. doi:S1876-2859(16)30534-4
- Higgins, J. P., & Green, S. (Eds.). (2011). *Cochrane handbook for systematic reviews of interventions* (Vol. 4). John Wiley & Sons. Retrieved from <http://handbook-5-1.cochrane.org/>
- Hilderson, D., Saidi, A. S., Van Deyk, K., Verstappen, A., Kovacs, A. H., Fernandes, S. M., ... Moons, P. (2009). Attitude toward and current practice of transfer and transition of adolescents with congenital heart disease in the United States of America and Europe. *Pediatric Cardiology*, 30(6), 786-793. doi:10.1007/s00246-009-9442-1
- Huang, J. S., Terrones, L., Tompane, T., Dillon, L., Pian, M., Gottschalk, M., . . . Bartholomew, L. K. (2014). Preparing adolescents with chronic disease for transition to adult care: A technology program. *Pediatrics*, 133(6), e1639-46. doi:10.1542/peds.2013-2830

MEASURES OF TRANSITION READINESS

- Ishida, Y., Tezuka, M., Hayashi, M., & Inoue, F. (2016). Japanese childhood cancer survivors' readiness for care as adults: A cross-sectional survey using the transition scales. *Psycho-Oncology, 26*(7), 1019-1026. doi:10.1002/pon.4276
- Javalkar, K., Fenton, N., Cohen, S., & Ferris, M. (2014). Peer Reviewed: Socioecologic factors as predictors of readiness for self-management and transition, medication adherence, and health care utilization among adolescents and young adults with chronic kidney disease. *Preventing Chronic Disease, 11*, e117. doi:10.5888/pcd11.140072
- Javalkar, K., Johnson, M., Kshirsagar, A. V., Ocegueda, S., Detwiler, R. K., & Ferris, M. (2016). Ecological factors predict transition Readiness/Self-management in youth with chronic conditions. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine, 58*(1), 40-46. doi:10.1016/j.jadohealth.2015.09.013
- Javalkar, K., Williamson, N., Vaidya, S., Vaidya, A., & Ferris, M. (2016). The association between educational resource utilization and knowledge/self-management among patients with type 2 diabetes in Pune, India. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews, 10*(4), 186-189. doi:10.1016/j.dsx.2016.06.002
- Jensen, P. T., Paul, G. V., LaCount, S., Peng, J., Spencer, C. H., Higgins, G. C., ... Ardoin, S. P. (2017). Assessment of transition readiness in adolescents and young adults with chronic health conditions. *Pediatric Rheumatology, 15*(1), 70-77. doi:10.1186/s12969-017-0197-6
- Johnson, M. A., Javalkar, K., van Tilburg, M., Haberman, C., Rak, E., & Ferris, M. E. (2015). The relationship of transition readiness, self-efficacy, and adherence to preferred health learning method by youths with chronic conditions. *Journal of Pediatric Nursing, 30*(5), 83-90. doi: 10.1016/j.pedn.2015.05.014

MEASURES OF TRANSITION READINESS

- Kaufman, M., & Pinzon, J. (2007). Transition to adult care for youth with special health care needs. *Paediatric Child Health, 12*(9), 785-788. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2532874/pdf/pch12785.pdf>
- Kızıler, E., Yıldız, D., & Eren, B. F. (2017). Validation of transition readiness assessment questionnaire in Turkish adolescents with diabetes. *Balkan Medical Journal, 35*, 93-100. doi:10.4274/balkanmedj.2016.1415
- Klassen, A. F., Grant, C., Barr, R., Brill, H., Kraus de Camargo, O., Ronen, G. M., ... Tsangaris, E. (2015). Development and validation of a generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions: the TRANSITION-Q. *Child: Care, Health and Development, 41*(4), 547-558. doi: 10.1111/cch.12207
- Klassen, A. F., Rosenberg-Yunger, Z. R., D'Agostino, N. M., Cano, S. J., Barr, R., Syed, I., ... Nathan, P. C. (2015). The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults. *Health Expectations, 18*(6), 1941-1955. doi: 10.1111/hex.12241
- Klostermann, N. R., McAlpine, L., Wine, E., Goodman, K. J., & Kroeker, K. I. (2018). Assessing the transition intervention needs of young adults with inflammatory bowel diseases. *Journal of Pediatric Gastroenterology and Nutrition, 66*(2), 281-285. doi:10.1097/MPG.0000000000001677
- Lerret, S. M., Menendez, J., Weckwerth, J., Lokar, J., Mitchell, J., & Alonso, E. M. (2012). Essential components of transition to adult transplant services: the transplant coordinators' perspective. *Progress in Transplantation, 22*(3), 252-258. doi:10.7182/pit2012110

MEASURES OF TRANSITION READINESS

- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P., ... & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *PLoS medicine*, *6*(7), e1000100.
- Little, J. M., Odiaga, J. A., & Minutti, C. Z. (2017). Implementation of a diabetes transition of care program. *Journal of Pediatric Health Care*, *31*, 215-221.
doi:10.1016/j.pedhc.2016.08.009
- Mackie, A. S., Islam, S., Magill-Evans, J., Rankin, K. N., Robert, C., Schuh, M., . . . Rempel, G. R. (2014). Healthcare transition for youth with heart disease: A clinical trial. *Heart (British Cardiac Society)*, *100*(14), 1113-1118. doi:10.1136/heartjnl-2014-305748
- Mackie, A. S., Rempel, G. R., Islam, S., Rankin, K., McCurdy, C., Vonder Muhll, I., ... Kovacs, A. H. (2016). Psychosocial maturity, autonomy, and transition readiness among young adults with congenital heart disease or a heart transplant. *Congenital Heart Disease*, *11*(2), 136-143. doi:10.1111/chd.12300
- MacLure, K., Paudyal, V., & Stewart, D. (2016). Reviewing the literature, how systematic is systematic? *International Journal of Clinical Pharmacy*, *38*(3), 685-694.
doi:10.1007/s11096-016-0288-3
- McDonagh, J. E. (2005). Growing up and moving on: Transition from pediatric to adult care. *Pediatric Transplantation*, *9*(3), 364-372. doi:10.1111/j.1399-3046.2004.00287.x
- McDonagh, J. E., & Kelly, D. A. (2007). Trans-plan-sition! Transplantation and transition. *Pediatric Transplantation*, *11*(6), 578-581. doi:10.1111/j.1399-3046.2007.00756.x
- Moynihan, M., Saewyc, E., Whitehouse, S., Paone, M., & McPherson, G. (2015). Assessing readiness for transition from paediatric to adult health care: Revision and psychometric

MEASURES OF TRANSITION READINESS

- evaluation of the Am I ON TRAC for Adult Care questionnaire. *Journal of Advanced Nursing*, 71(6), 1324-1335. doi:10.1111/jan.12617
- Nazareth, M., Hart, L., Ferris, M., Rak, E., Hooper, S., & Van Tilburg, M. A. (2017). A parental report of youth transition readiness: The Parent STARx questionnaire (STARx-P) and re-evaluation of the STARx child report. *Journal of Pediatric Nursing*, 38, 122-126. doi:10.1016/j.pedn.2017.08.033
- Nguyen, T., Henderson, D., Stewart, D., Hlyva, O., Punthakee, Z., & Gorter, J. W. (2016). You never transition alone! Exploring the experiences of youth with chronic health conditions, parents and healthcare providers on self-management. *Child: Care, Health and Development*, 42(4), 464-472. doi:10.1111/cch.12334
- Okumura, M. J., Ong, T., Dawson, D., Nielson, D., Lewis, N., Richards, M., . . . Kleinhenz, M. E. (2014). Improving transition from paediatric to adult cystic fibrosis care: Programme implementation and evaluation. *BMJ Quality & Safety*, 23 Suppl 1, i64-i72. doi:10.1136/bmjqs-2013-002364
- Polfuss, M., Babler, E., Bush, L. L., & Sawin, K. (2015). Family perspectives of components of a diabetes transition program. *Journal of Pediatric Nursing*, 30(5), 748-756. doi:10.1016/j.pedn.2015.05.010
- Prior, M., McManus, M., White, P., & Davidson, L. (2014). Measuring the “triple aim” in transition care: A systematic review. *Pediatrics*, 134(6), 1648-1661. doi:10.1542/peds.2014-1704
- Ramos, A. L., Hoffmann, F., Albrecht, K., Klotsche, J., Zink, A., & Minden, K. (2017). Transition to adult rheumatology care is necessary to maintain DMARD therapy in young

MEASURES OF TRANSITION READINESS

- people with juvenile idiopathic arthritis. *In Seminars in Arthritis and Rheumatism*, 47(2), 269-275. doi:10.1016/j.semarthrit.2017.05.003
- Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing outlook*, 57(4), 217-225. doi: <https://doi.org/10.1016/j.outlook.2008.10.004>
- Sawicki, G. S., Garvey, K. C., Toomey, S. L., Williams, K. A., Chen, Y., Hargraves, J. L., ... Finkelstein, J. A. (2015). Development and validation of the adolescent assessment of preparation for transition: A novel patient experience measure. *Journal of Adolescent Health*, 57(3), 282-287. doi:10.1016/j.jadohealth.2015.06.004.
- Sawicki, G. S., Garvey, K. C., Toomey, S. L., Williams, K. A., Hargraves, J. L., James, T., ... Finkelstein, J. A. (2017). Preparation for transition to adult care among Medicaid-insured adolescents. *Pediatrics*, 140(1), 1-9. doi:10.1542/peds.2016-2768
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I. C., Livingood, W., ... Wood, D. (2009). Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire. *Journal of Pediatric Psychology*, 36(2), 160-171. doi:10.1093/jpepsy/jsp128
- Schwartz, L. A., Brumley, L. D., Tuchman, L. K., Barakat, L. P., Hobbie, W. L., Ginsberg, J. P., ... & Deatrick, J. A. (2013). Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatrics*, 167(10), 939-946. doi:10.1001/jamapediatrics.2013.2223
- Schwartz, L. A., Daniel, L. C., Brumley, L. D., Barakat, L. P., Wesley, K. M., & Tuchman, L. K. (2014). Measures of readiness to transition to adult health care for youth with chronic physical health conditions: A systematic review and recommendations for measurement

MEASURES OF TRANSITION READINESS

testing and development. *Journal of Pediatric Psychology*, 39(6), 588-601.

doi:10.1093/jpepsy/jsu028

Schwartz, L. A., Hamilton, J. L., Brumley, L. D., Barakat, L. P., Deatrick, J. A., Szalda, D. E., ...

Kazak, A. E. (2017). Development and content validation of the transition readiness inventory item pool for adolescent and young adult survivors of childhood cancer. *Journal of Pediatric Psychology*, 42(9), 983-994. doi:10.1093/jpepsy/jsx095

Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: care, health and development*, 37(6), 883-895. doi: 10.1111/j.1365-2214.2011.01282.x

Seeley, A., & Lindeke, L. (2017). Developing a transition care coordination program for youth with spina bifida. *Journal of Pediatric Health Care: Official Publication of National Association of Pediatric Nurse Associates & Practitioners*, 31(6), 627-633.

doi:10.1016/j.pedhc.2017.04.015

Sobota, A., Akinlonu, A., Champigny, M., Eldridge, M., McMahon, L., Telfair, J., & Sprinz, P. (2014). Self-reported transition readiness among young adults with sickle cell disease. *Journal of Pediatric Hematology/Oncology*, 36(5), 389-394.

doi:10.1097/MPH.0000000000000110

Speller-Brown, B., Kelly, K. P., VanGraafeiland, B., Feetham, S., Sill, A., Darbari, D., & Meier, E. R. (2015). Measuring transition readiness: A correlational study of perceptions of parent and adolescents and young adults with sickle cell disease. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, 30(5), 788-796.

doi:10.1016/j.pedn.2015.06.008

MEASURES OF TRANSITION READINESS

Stewart, K. T., Chahal, N., Kovacs, A. H., Manlhiot, C., Jelen, A., Collins, T., & McCrindle, B.

W. (2017). Readiness for transition to adult health care for young adolescents with congenital heart disease. *Pediatric Cardiology*, doi:10.1007/s00246-017-1580-2

Stinson, J., Kohut, S. A., Spiegel, L., White, M., Gill, N., Colbourne, G., ... Hazel, B. (2014). A

systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *International Journal of Adolescent Medicine and Health*, 26(2), 159-174. doi:10.1515/ijamh-2013-0512.

Stollon, N., Zhong, Y., Ferris, M., Bhansali, S., Pitts, B., Rak, E., ... van Tilburg, M. A. (2017).

Chronological age when healthcare transition skills are mastered in adolescents/young adults with inflammatory bowel disease. *World Journal of Gastroenterology*, 23(18), 3349. doi:10.3748/wjg.v23.i18.3349

Szalda, D., Piece, L., Brumley, L., Li, Y., Schapira, M. M., Wasik, M., ... & Schwartz, L. A.

(2017). Associates of engagement in adult-oriented follow-up care for childhood cancer survivors. *Journal of Adolescent Health*, 60(2), 147-153.

doi:10.1016/j.jadohealth.2016.08.018

Telfair, J., Alexander, L. R., Loosier, P. S., Alleman-Velez, P. L., & Simmons, J. (2004).

Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *Journal of Health Care for the Poor and Underserved*, 15(3), 443-461. doi:10.1353/hpu.2004.0049

Tepper, V., Zaner, S., & Ryscavage, P. (2017). HIV healthcare transition outcomes among youth

in North America and Europe: a review. *Journal of the International AIDS Society*, 20(Suppl 3), 60-70. doi:10.7448/IAS.20.4.21490

MEASURES OF TRANSITION READINESS

Treadwell, M., Johnson, S., Sisler, I., Bitsko, M., Gildengorin, G., Medina, R., . . . Smith, W. R.

(2016a). Development of a sickle cell disease readiness for transition assessment.

International Journal of Adolescent Medicine and Health, 28(2), 193-201.

doi:10.1515/ijamh-2015-0010

Treadwell, M., Johnson, S., Sisler, I., Bitsko, M., Gildengorin, G., Medina, R., . . . Smith, W. R.

(2016b). Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *International Journal of Adolescent Medicine and Health*, 28(4), 381-388.

doi:10.1515/ijamh-2015-0014

Trivedi, I., Holl, J. L., Hanauer, S., & Keefer, L. (2016). Integrating adolescents and young

adults into adult-centered care for IBD. *Current Gastroenterology Reports*, 18(5), 21-30.

doi:10.1007/s11894-016-0495-z

Uzark, K., Smith, C., Donohue, J., Yu, S., Afton, K., Norris, M., & Cotts, T. (2015). Assessment

of transition readiness in adolescents and young adults with heart disease, *The Journal of Pediatrics*, 167(6), 1233-1238. doi:10.1016/j.jpeds.2015.07.043

Van Staa, A., & Sattoe, J. N. (2014). Young adults' experiences and satisfaction with the transfer of care. *Journal of Adolescent Health*, 55(6), 796-803.

doi:10.1016/j.jadohealth.2014.06.008

Wood, D. L., Sawicki, G. S., Miller, M. D., Smotherman, C., Lukens-Bull, K., Livingood, W. C.,

... & Kraemer, D. F. (2014). The Transition Readiness Assessment Questionnaire

(TRAQ): Its factor structure, reliability, and validity. *Academic Pediatrics*, 14(4), 415-

422. doi:10.1016/j.acap.2014.03.008

MEASURES OF TRANSITION READINESS

- Yeung E., Kay J., Roosevelt, G.E., Brandon, M., & Yetman, A.T. (2008). Lapse of care as a predictor for morbidity in adults with congenital heart disease. *International Journal of Cardiology*, *125*(1),62–5. doi:10.1016/j.ijcard.2007.02.023
- Zelikovsky, N., Schast, A. P., Palmer, J., & Meyers, K. E. (2008). Perceived barriers to adherence among adolescent renal transplant candidates. *Pediatric Transplantation*, *12*(3), 300-308. doi:10.1111/j.1399-3046.2007.00886.x
- Zhang, L. F., Ho, J. S., & Kennedy, S. E. (2014). A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatrics*, *14*(1), 4-14. doi:10.1186/1471-2431-14-4
- Zhou, H., Roberts, P., Dhaliwal, S., & Della, P. (2016). Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services—an integrative review. *Journal of clinical nursing*, *25*(21-22), 3113-3130. doi:10.1111/jocn.13326

MEASURES OF TRANSITION READINESS

APPENDIX A

Project Notebook- available upon request.

APPENDIX B

Phase Two Screening Tool

Confidential

Transition Measures Systematic Review
Page 1 of 1

Screening Phase 2 - Title and Abstract

Record ID _____

Citation

First author's last name _____

Year of publication _____

Is the full text in English, or has it been translated to English? Yes
 No
(If NO, refer article to the PI for possible translation)

Inclusion Criteria

- 1) Report of research published between 2014 and now 1 Yes
 2 No
 3 Unclear
- 2) Study population includes youth
2a) between 11 and 25 years of age. 1 Yes
 2 No
 3 Unclear
- 2b) with health condition that originated in childhood and requires life-long specialized care. 1 Yes
 2 No
 3 Not clear
- 3) Study developed, discussed and/or assessed measurements and/or tools for assessing transition readiness. 1 Yes
 2 No
 3 Unclear
- 4) Study discussed the development and psychometric properties of the measure. 1 Yes
 2 No
 3 Unclear

5) Reviewer Comments _____

Decision

6a) Reviewer Decision 1 Include
 2 Exclude
 3 Unsure

If Unsure or if there is disagreement between reviewers, record will be discussed at consensus meeting and final decision will be reached.

7) Final decision: review the full text of the article. Yes-include No- exclude

APPENDIX C

Phase Three Screening Tool

Confidential

Transition Measures Systematic Review
Page 1 of 1

Screening Phase 3 - Full article

Record ID _____

Date _____

Citation

First author's last name _____

Year of publication _____

Is the full text in English, or has it been translated to English? Yes
 No
(If NO, refer article to the PI for possible translation)

Inclusion Criteria

- 1) Report of research published between 2014 and now 1 Yes
 2 No
 3 Unclear
- 2) Study population includes youth 1 Yes
2a) between 11 and 25 years of age. 2 No
 3 Unclear
- 2b) with health condition that originated in childhood and requires life-long specialized care. 1 Yes
 2 No
 3 Not clear
- 3) Study developed, discussed and/or assessed measurements and/or tools for assessing transition readiness. 1 Yes
 2 No
 3 Unclear
- 4) Study discussed the development and psychometric properties of the measure. 1 Yes
 2 No
 3 Unclear

5) Reviewer Comments _____

Decision

6a) Reviewer Decision 1 Include
 2 Exclude
 3 Unsure

If Unsure or if there is disagreement between reviewers, record will be discussed at consensus meeting and final decision will be reached.

7) Final decision: include article in systematic review. Yes-include No- exclude

MEASURES OF TRANSITION READINESS

APPENDIX D

Data Extraction Tool

Data Extraction- Screening Phase 4

Page 1 of 6

Record ID _____

Record ID _____

Form completed on _____

Citation Information

First author's last name _____

Title of article _____

Title of Tool _____

Journal _____

Year of publication _____

Country or origin _____

Study Design (if stated) _____

Disease specific or Non disease specific? a. Disease specific
 b. Non disease specific

Original language of article _____

Language versions of article _____

Is this the original report on the instrument or a validation/reliability study or both? Original report (first article that introduces the TOOL)
 Validation/Reliability study (Stated in the AIM/Purpose)
 Previously developed tool being researched
 Unclear

Page 1 of 6

In your own words, describe your answer above: _____

Did the author specify a theory on which the tool is based? If so, please state: _____

State the languages the tool is available in: _____

What is the tool measuring? (ex. satisfaction with transition, clinical status, functional ability, criteria for transition, problems experienced by patients, ect) _____

Measurement concepts/domains (for example: knowledge, behaviour, prior thought, difficulty, skills for self-advocacy, skills for self-management, medications, adherence) _____

Psychometric properties: (content validity, inter-rater reliability) _____

What are the limitations of the study? _____

Number of items (questions) _____

Tool completed by: 1 Patient
 2 Parent
 3 Provider

Type of Questions Likert scale
 Questionnaire
 Interview
 Other - Please specify

Other: _____

What value(s) of measurement are given? _____

Time to complete instrument _____

MEASURES OF TRANSITION READINESS

Page 3 of 6

Description of the Study Population	
Number of participants	_____
Age (mean, median, and range if provided)	_____
How many males?	_____
How many females?	_____
Diagnoses and number in each diagnostic group	_____
Participants age at diagnosis	_____
Participants age at transfer	_____
Timing of outcome assessment	_____
Comment on patient characteristics	_____
Dropouts/Response Rate	_____

Conceptual Framework: The Triple Aim	
Did the article discuss any of the components of the "Triple Aim theory"? Please check any (all) that apply.	<input type="checkbox"/> a. Patient Experience of Care <input type="checkbox"/> b. Population Health <input type="checkbox"/> c. Per Capita Cost
Which aspects of experience of care are addressed?	<input type="checkbox"/> a. satisfaction <input type="checkbox"/> b. barriers to care <input type="checkbox"/> c. likelihood to recommend <input type="checkbox"/> d. effective <input type="checkbox"/> e. patient-centered <input type="checkbox"/> other
If other was chosen, please specify?	_____

Page 4 of 6

What aspects of population health are addressed?	<input type="checkbox"/> a. mortality <input type="checkbox"/> b. life expectancy <input type="checkbox"/> c. psychological factors (blood pressure, BMI, blood glucose, cholesterol) <input type="checkbox"/> d. behavioural factors (smoking, alcohol consumption, physical activity, diet) <input type="checkbox"/> e. other
If other was chosen, please specify?	_____
What aspects of per capita cost are addressed?	<input type="checkbox"/> a. total cost for the AYA <input type="checkbox"/> b. utilization of services <input type="checkbox"/> c. other
If other was chosen, please specify?	_____
Any additional comments on the "Triple Aim":	_____

Conceptual Framework: SMART	
Are the following factors discussed/explored?	<input type="checkbox"/> a. knowledge <input type="checkbox"/> b. skills/self-efficacy <input type="checkbox"/> c. Beliefs/expectations <input type="checkbox"/> d. Developmental maturity <input type="checkbox"/> e. Goals/Motivation <input type="checkbox"/> f. Relationships/communication <input type="checkbox"/> g. Psychosocial/emotions
Are the following factors explored/discussed?	<input type="checkbox"/> a. Sociodemographic/culture <input type="checkbox"/> b. Access/insurance <input type="checkbox"/> c. Medical Status and Risk <input type="checkbox"/> d. Neurocognitive/IQ
Any additional comments on the "SMART" model?	_____
Does the measure look at more than just the patient? (physician, parent, multi-disciplinary team members)	_____
Additional comments about tool:	_____
Additional reviewer comments:	_____

MEASURES OF TRANSITION READINESS

Cohen Criteria- based on the TOOL (not the research study)-		
	Yes	No
The measure must have been presented in at least two peer-reviewed articles by different investigators or investigatory teams	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request)	<input type="checkbox"/>	<input type="checkbox"/>
Detailed (e.g., statistics presented) information indicating good validity and reliability in at least one peer-reviewed article	<input type="checkbox"/>	<input type="checkbox"/>

Approaching well-established assessment		
	Yes	No
The measure must have been presented in at least two peer-reviewed articles, which might be by the same investigator or investigatory team	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request)	<input type="checkbox"/>	<input type="checkbox"/>
Validity and reliability information presented in either vague terms (e.g., no statistics presented) or moderate values	<input type="checkbox"/>	<input type="checkbox"/>

Promising assessment		
	Yes	No
The measure must have been presented in at least one peer-reviewed article	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request)	<input type="checkbox"/>	<input type="checkbox"/>
Validity and reliability information presented in either vague terms (e.g., no statistics presented) or moderate values	<input type="checkbox"/>	<input type="checkbox"/>

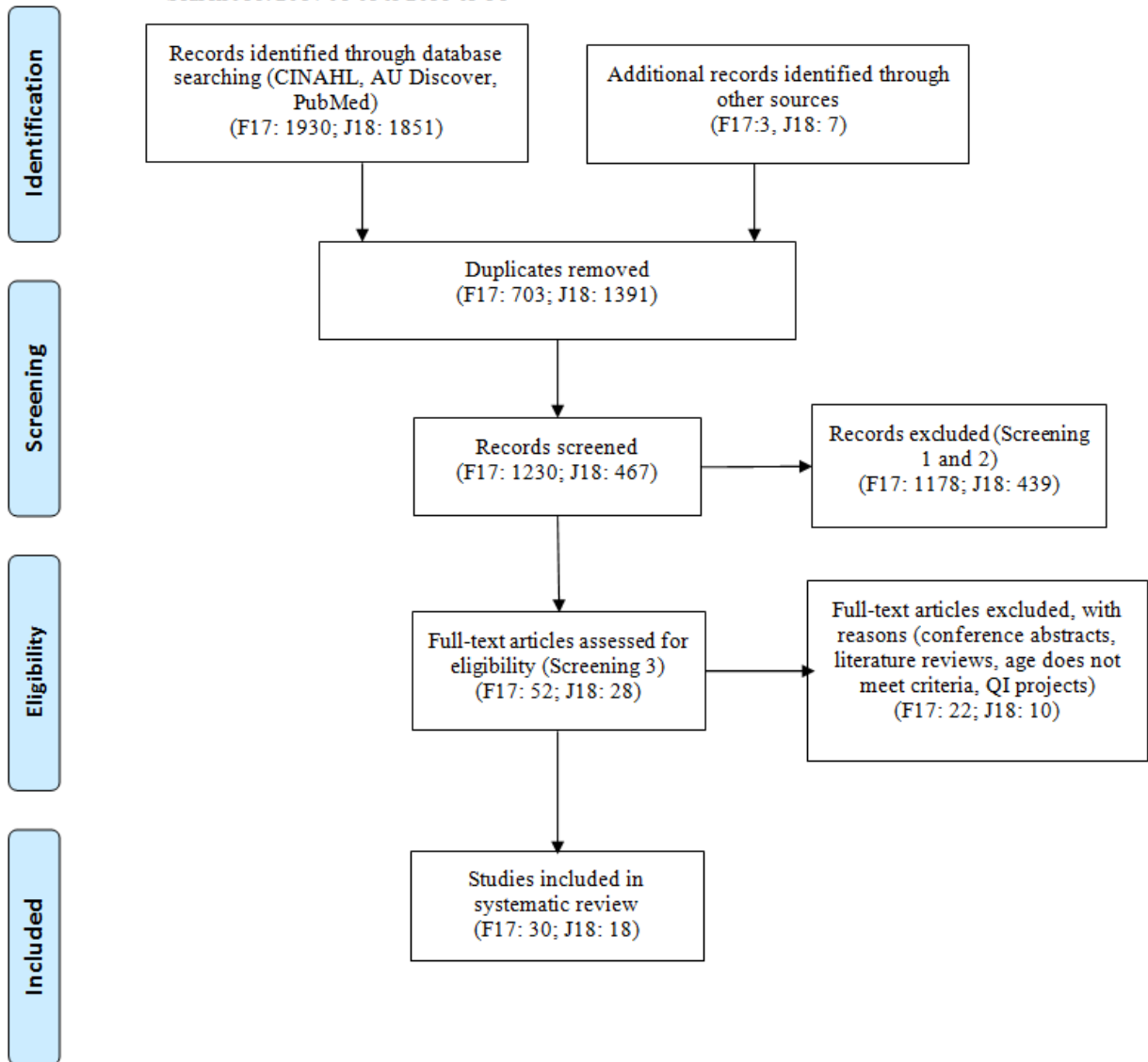
APPENDIX E

PRISMA Diagram



PRISMA 2009 Flow Diagram

Search F17: 2014-01-01 to 2017-02-26
 Search J18: 2014-01-01 to 2018-03-31



MEASURES OF TRANSITION READINESS

Table 2

Characteristics of Transition Readiness Measures

Name of Tool, Disease - specific or neutral, country of origin	Author (first name, date)	Original language; translated languages of tool	Target Population	Measurement concepts/domains	Number of Items	Who completes the survey?	Cohen Criteria; is the tool validated?
<i>Well-established n = 7</i>							
Transition Readiness Assessment Questionnaire (TRAQ 4.1) Disease-neutral United States	Grady et al., (2018) Hart et al., (2016) Huang et al., (2014) Jensen et al., (2017) Mackie, Islam, et al., (2014) Mackie, Rempel, et al., (2016) Okumura et al., (2014) Stewart et al., (2017) Szalda et al., (2017)	English	Adolescents (age=16–26 years) with special healthcare needs/wide variety of complex health conditions	1. Self-advocacy 2. Chronic disease self-management	29	Patient; self-report	Well-established Validated

MEASURES OF TRANSITION READINESS

Transition Readiness Assessment Questionnaire (TRAQ 5.0) Disease-neutral United States	Anelli et al., (2018) Beal et al., (2016) Gonzalez et al., (2017) Kiziler et al., (2017) Klostermann et al., (2018) Little et al., (2017) Seeley & Lindeke, (2017) Wood et al., (2014)	Original language English, available in Brazilian Portuguese, Turkish and Argentinian Spanish	Adolescents 14-21 with special healthcare needs.	Five factor structures: 1. Managing medications, 2. Keeping appointment, 3. Tracking health issues 4. Talking with providers, 5. Managing daily activities.	20	Patient; self-report	Well-established Validated
Self-Management and Transition to Adulthood with the Rx= Treatment (STARx) Disease-neutral United States	Benson et al., (2018) Cohen et al., (2015) Eluri et al., (2017) Ferris, Cohen, et al., (2015) Johnson et al., (2015) Nazareth et al., (2017)	English	Adolescents and young adults (12 to 25) with chronic conditions	1. Medication management 2. Provider communication 3. Engagement during appointments 4. Disease knowledge 5. Adult Health responsibilities 6. Resource Utilization	18	Patient (parent version available); self-report	Well-established Validated

MEASURES OF TRANSITION READINESS

UNC TRxANSITION	Cantu-Quintanilla et al., (2015) Fenton et al., (2015) Javalkar et al., (2014) Javalkar et al., (2016)	English, translated to Spanish	AYA diagnosed with a chronic condition	Ten domains: 1. Type of Illness 2. Knowledge about medications and adherence 3. Disease, 4. Nutrition, 5. Insurance, 6. Reproductive health, 7. Disease self-management 8. Self-activation. 9. New health care providers 10. Ongoing support	33 (Spanish version 32)	Patient; provider administered	Well established Validated
Readiness to Transition Questionnaire (RTQ)	Beal et al., (2016) Gumidyala et al., (2018) Speller-Brown et al., (2015)	English	Originally developed for adolescents 16-22 with kidney transplants and their parents	1. RTQ-Overall, 2. RTQ-Adolescent Responsibility, RTQ-Parent involvement	22	Patient; self-report (parallel parent version)	Well-established Validated
AM I ON TRAC	Gravelle et al., (2015) Moynihan et al., (2015)	English	Adolescents 12-19 with chronic health conditions	1. Knowledge scale 2. Behaviour Index	25	Patient; self-report	Well-established Validated
Responsibility and Familiarity with Illness Survey (REFILS)	Annunziato et al., (2018)	English	Adolescents 9-17 who have had a liver transplant	2 domains: 1. Perceived knowledge about the illness 2. Responsibility for medical management.	13	Patient; self-report	Well-established Initial validation reported

MEASURES OF TRANSITION READINESS

Disease-specific							
United States							
<i>Approaching well-established n = 5</i>							
Transition Scales	Ishida et al., (2016)	English, available in Japanese	Adolescents and young adults 15 to 26 years who are childhood cancer survivors	1. 6-item Cancer worry scale 2. 15-item self-management skills scale 3. 12-item expectations scale	33	Patient; self-report	Approaching well-established Validated
Disease-specific	Klassen et al., (2015)						
Canada							
Adolescent Assessment of Preparation for Transition (ADAPT)	Sawicki et al., (2015) Sawicki et al., (2017)	English, available in Spanish	16-17-year-old adolescents with chronic health conditions	1. Counseling on transition self-management; 2. Counseling on prescription medication; 3. Transfer planning	26	Patient; self-report	Approaching well-established Validated
Disease-neutral							
United States							
Transition Intervention Program Readiness for Transition (TIP-RFT)	Treadwell et al., (2016a) Treadwell et al., (2016b)	English	AYA with Sickle Cell Disease	1. Healthcare Knowledge and Skills 2. Education and vocational planning 3. Social Support Skill set 4. Independent Living Skills	22	Patient; self-report	Approaching well-established Validated
Disease-specific							
United States							

MEASURES OF TRANSITION READINESS

<p>Transition Readiness Inventory Item Pool (TRI)</p> <p>Disease-specific</p> <p>United States</p>	<p>Schwartz et al., (2015)</p>	<p>English</p>	<p>AYA childhood cancer survivors</p>	<p>11 SMART components</p> <p><i>Pre-existing factors</i> (Objective factors less amenable to intervention)</p> <p>Socio-demographics/culture</p> <p>Access/insurance</p> <p>Medical status and risk</p> <p>Neurocognitive/IQ</p> <p><i>Modifiable variables:</i></p> <p>Knowledge</p> <p>Skills/self-efficacy</p> <p>Beliefs/expectations</p> <p>Developmental maturity (patient only)</p> <p>Goals/motivation</p> <p>Relationships/communication</p> <p>Psychosocial/emotions</p>	<p>81 content valid items; 85 items for parent</p>	<p>Patient, parents; self-report</p>	<p>Approaching well-established</p> <p>Not validated</p>
<p>Transition Intervention Program Readiness for Transition (TIP-RFT)</p> <p>Disease-specific</p> <p>United States</p>	<p>Treadwell et al., (2016a)</p> <p>Treadwell et al., (2016b)</p>	<p>English</p>	<p>AYA with Sickle Cell Disease</p>	<ol style="list-style-type: none"> 1. Healthcare Knowledge and Skills 2. Education and vocational planning 3. Social Support Skill set 4. Independent Living Skills 	<p>22</p>	<p>Patient; self-report</p>	<p>Approaching well-established</p> <p>Validated</p>

MEASURES OF TRANSITION READINESS

<i>Promising assessment n = 4</i>							
Healthcare Needs Scale for Youth with Congenital Heart Disease (HNS-CHD) Disease-specific Taiwan	Chen et al., (2018)	Mandarin	Adolescents with congenital heart disease, 15-24 years	<ol style="list-style-type: none"> 1. Health management 2. Health policy; 3. individual and interpersonal relationships 	25	Patient; self-report	<p>Promising assessment</p> <p>Initial validation reported</p>
CHD Readiness Transition Assessment Disease-specific United States	Uzark et al., (2015)	English	Adolescents 13-25 years and parents of children 13-18 with congenital heart disease or heart transplant	<ol style="list-style-type: none"> 1. Perceived knowledge domain 2. Self-management 3. Self-efficacy 	Varies based on gender and medications	Patient, parent self-report	<p>Promising assessment</p> <p>Initial validation reported</p>
On your own feet transfer experience scale (OYOF-TES) Disease-neutral The Netherlands	VanStaa et al., (2017)	English	Adolescents 18-25 with various chronic conditions	<ol style="list-style-type: none"> 1. Perceived alignment and collaboration between PC and AC 2. Experienced preparation for transfer including readiness, timing, and co-decision making 	18	Patient; self-report	<p>Promising assessment</p> <p>Not validated</p>

MEASURES OF TRANSITION READINESS

No title- from Moving on Binder	Polfuss et al., (2015)	English	Adolescents with diabetes and parent dyads	<ol style="list-style-type: none"> 1. Diabetes knowledge 2. Adolescents diabetes self-efficacy 3. Family members perceptions of how important specific knowledge or skills were in preparing the adolescent for transition to adult care 4. Perceptions of 8 areas of adolescent preparation for transition and their ability to self-manage diabetes 5. Evaluation of how helpful specific aspects of the program were 	59	Patient, parent-self report	<p>Promising assessment</p> <p>Not validated</p>
Disease-specific							
United States							
<i>Does not meet Cohen criteria n = 3</i>							
Sickle cell transition intervention program skills checklists	Sobota et al., (2014)	English	Adolescents 18-22 with Sickle Cell Disease being seen in a transition program	<p>Five knowledge skill sets</p> <ol style="list-style-type: none"> 1. Medical 2. Educational/Vocational 3. Health Benefits 4. Social 5. Independent Living <p>Psychological checklists</p> <ol style="list-style-type: none"> 1. Self-efficacy 2. Sickle cell stress 	85	Patient; self-report	<p>Does not meet Cohen criteria</p> <p>Not validated</p>
Disease-specific							
English							

MEASURES OF TRANSITION READINESS

				3. Feelings about transition			
The Adolescent Autonomy Checklist (SCD-AAD)	Abel et al., (2015)	English	Adolescents 13-21 with Sickle Cell Disease	<ol style="list-style-type: none"> 1. Kitchen 2. Nutrition 3. Laundry 4. Housekeeping 5. Emergency 6. Personal Skills 7. Health care skills 8. Sexual development 9. Money management 10. Leisure skills 11. Vocational skills 12. Living arrangements 	100	Patient; self-report	<p>Does not meet Cohen criteria</p> <p>Not validated</p>
Disease-specific United States							
No title-Fontan Procedure-in house questionnaire	Du Plessis et al., (2017)	English	Adolescents 15-18 with congenital heart disease who have undergone a series of operations resulting in the Fontan surgical procedure, and their parents	Health knowledge, medication management, experiences of paediatric healthcare services (including engagement with cardiologists), and readiness for transition.	NR	Patient, parents; self-report	<p>Does not meet Cohen criteria</p> <p>Not validated</p>
Disease-specific Australia							