

**Healthcare Transition in Adolescents with Heart Disease:  
Assessing Transition Readiness**

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### Abstract

**Problem & Purpose:** The American Heart Association, American Academy of Pediatrics, and American Academy of Family Physicians recommend the use of formal transition interventions to support adolescent and young adult (AYA) patients transitioning to adult care. Within a pediatric cardiology clinic in an urban, academic medical center approximately 25% of the patient population is over the age of 16 years. The clinic has no structured transition policy or program and only 2.4% of these patients received documented transition education. The purpose of this quality improvement project was to implement a transition readiness assessment with the goal of ensuring 100% of eligible patients received transition education or appropriate referral to adult services. **Methods:** Implementation occurred over a 17-week period. Patients over 16 years with ongoing cardiac needs and stable treatment plans were eligible; patients new to the practice were excluded. During a routine cardiology appointment, eligible patients received an introductory letter and QR code for self-administration of the Transition Readiness Assessment Questionnaire (TRAQ). Following completion of the TRAQ tool, a nurse practitioner reviewed the readiness score, and patients received a transition focused appointment or referral to adult services, as appropriate. Eligibility was determined and demographic data obtained via chart audits. **Results:** Adherence to delivery of the TRAQ tool to eligible patients was high (88%). A total of 17 of 52 eligible patients elected to participate by completing the readiness assessment (n=17). Chart audits of the implementation period demonstrate 35% of patients 16 years and older having documented transition education or referral to adult care. **Conclusions:** Successful change in practice at the site demonstrates the feasibility of transition initiatives. Findings suggest that implementation of a transition readiness assessment can increase appropriate management of AYA patients.

## **Healthcare Transition in Adolescents with Heart Disease: Assessing Transition Readiness**

In the last several decades the number of adults with congenital heart disease (CHD) has surpassed the number of children living with these conditions (Everitt et al., 2017). As more patients survive to adulthood they require lifelong specialty care. Healthcare transition is a process that takes place over many years, wherein AYA patients develop increasing autonomy and assume responsibility for management of their medical conditions (John et al., 2022). The transition period should include the actual transfer, when care moves to adult providers.

Healthcare transition is a vulnerable time and patients are at increased risk for care discontinuity and medical complications (John et al., 2022). A systematic review and meta-analysis performed by Moons et al. (2022) showed that in the United States up to 34% of patients with CHD experience some care discontinuity around the time of transition. There are many adverse outcomes associated with mismanaged transition including increased rate of unplanned admissions and cardiac procedures, decreased self-management skills, lower rates of patient satisfaction, and inappropriate healthcare resource utilization (Moons et al., 2022; Schmidt et al., 2020).

This Doctor of Nursing Practice (DNP) quality improvement (QI) project sought to assess transition readiness and improve healthcare transition for AYA patients at a pediatric cardiology clinic within an urban, academic medical center. Prior to implementation, the clinic did not have a structured transition program and provider judgement determined transition timing (C. Bonomo, personal communication, October 18, 2021). The author conducted a chart review, finding from September to November 2021, only 2.7% of patients aged 16 years and older

received documented transition education or referrals to adult care, leaving the vast majority of patients vulnerable to care discontinuity and poor outcomes (Schmidt et al., 2020).

A fishbone diagram (see Figure 1) was developed to explore root causes. Multiple factors contribute to this problem. A structured transition program addresses many of these factors (Schmidt et al., 2020; Uzark et al., 2020). Assessing transition readiness is a key part of a comprehensive program that supports AYA patients in the transition to adult providers (East Tennessee State University [ETSU], n.d.). The purpose of this QI project was the implementation of a transition readiness assessment to ensure delivery of transition education and appropriate referral to adult cardiology services.

### **Available Knowledge**

Multiple professional organizations including the American Heart Association (AHA), the American Academy of Pediatrics (AAP), and the American Academy of Family Physicians (AAFP) recommend structured healthcare transition programs as standard of care to ensure positive outcomes, especially for youth with special healthcare needs (Everitt et al., 2017). In a recent scientific statement, the American Heart Association recommended transition management as part of best practice in pediatric cardiology care, though implementation is inconsistent (John et al., 2022).

Evidence review (see Table 1) and synthesis (see Table 2) were created to summarize the literature supporting this initiative. Mackie et al. (2018) in a cluster randomized trial, and Schmidt et al. (2020) in a systematic review, demonstrate that structured HCT programs can improve health outcomes in AYA patients. Uzark et al. (2015, 2020) support transition readiness assessment as an essential part of structured transition programs. Mackie et al. (2018) represents a Level I experimental of good quality. Other studies included in the evidence synthesis are

Level III and include systematic reviews of experimental and non-experimental studies, quantitative cross-sectional research studies, and a prospective cohort study. This body of evidence supports the efficacy of structured transition interventions for AYA patients and the inclusion of transition readiness assessment as part of comprehensive programs.

A well-established and validated transition readiness tool was chosen for this QI project. The latest version of the Transition Readiness Assessment Questionnaire (TRAQ) developed by Wood et al. (2020) was selected (see Appendix A). The TRAQ tool demonstrates superior reliability and validity compared to other transition readiness assessment tools, which is upheld by this body of evidence (Johnson et al., 2021; Parfeniuk et al., 2020; Wood et al., 2014). The TRAQ assesses transition readiness on a five-point Likert scale using 20 items, across four domains, with two additional questions designed to assess motivation and confidence related to healthcare transition (Johnson et al., 2021). Necessary registration was completed prior to utilization of the TRAQ tool.

### **Rationale**

Project implementation was guided by the Promoting Action on Research Implementation in Health Services (PARIHS) framework (see Figure 2), a knowledge translation process framework developed by Kitson et al. (2008). According to PARIHS, successful implementation of QI is a function of evidence, facilitation, and context; facilitation is key for project success. In 2013, the site sought to address adolescent healthcare transition. At the time, implementation stalled due to staffing re-organization and lack of structured facilitation (B. Sherfy, personal communication, January 27, 2022). For this project, the DNP project lead (PL) actively facilitated implementation, adaptation to context, and establishment of sustainability plans.

## **Methods**

### **Context**

This pediatric cardiology clinic has a total of six physician providers, two nurse practitioners (NPs), and five core clinic staff members consisting of a registered nurse (RN), medical assistants (MAs), and administrative staff. There is an adult congenital heart disease (ACHD) physician and NP who provide services in a separate clinic within the same medical center. Prior to implementation there were changes in physician leadership that highlighted the importance of having a structured transition plan to ensure continuity of care.

Prior to implementation clinic workflows were analyzed, and a process map was created to guide changes and minimize disruption (see Figure 3). Due to appointment time restraints, selecting a self-administered tool—such as the TRAQ—was important. Ensuring capture of all eligible patients was carefully considered. The clinic sees about 200 patients a month, 25% of which are between the ages of 16 to 23 years (B. Sherfy, personal communication, January 21, 2022). An electronic health record (EHR) query was utilized to identify potentially eligible patients. The PL performed review of schedules to verify all eligible patients were approached to participate.

### **Intervention**

Implementation occurred over a 17-week period with education and training for providers and staff during week one. Training consisted of a review of adolescent healthcare transition principles, discussion of the TRAQ tool, and a review of the process and individual roles. Education and training were provided by the PL with participation from physician and NP providers, clinic staff, and cardiac sonographers.

As shown in the implementation process map (see Figure 3) a weekly EHR query was performed. The PL performed chart review to determine eligibility. Initial eligibility criteria included patients over 16 years of age with a CHD diagnosis, who are English speaking and medically stable (i.e., no planned surgeries or catheterizations and no unplanned admissions within six months). Numbers of eligible patients were lower than expected and in week four eligibility was expanded to include patients with a non-CHD diagnosis such as those with arrhythmias, hyperlipidemia, or acquired heart disease. Eligible patients were approached by PL, NP, or trained clinic staff during a routine follow-up appointment and given an introductory letter containing a QR code (see Appendix B) linking to the TRAQ on the Research Electronic Data Capture (REDCap) database.

Completed TRAQ tools were scored by the PL and scores were provided to NPs and the primary cardiologist for review. Patients scoring <4 on the TRAQ (demonstrating a lack of transition readiness) were contacted to schedule a transition focused telehealth appointment with the pediatric cardiology NP (East Tennessee State University [ETSU], n.d.). Patients with TRAQ score 4–5 (those demonstrating readiness) were referred to adult cardiology services upon review with the primary cardiologist.

Weekly on-site presence by the PL in all weeks of implementation facilitated adherence to the process change. Audits were performed weekly to ensure all eligible patients were captured. A core coalition of project team members met bi-weekly to evaluate progress and facilitate success.

## **Measurement**

Structure, process, and outcome goals of this project are presented in Table 3. Structure goals included training providers and staff and ensuring availability of project materials. Process

goals included 100% adherence to delivery of the TRAQ tool to eligible patients, patient participation, and score review by a provider. Multiple factors influence patient willingness to participate in transition interventions (Werner et al., 2019). Measuring the rate of tool delivery, in addition to patient participation, was important for establishing adherence and feasibility of the process change.

Outcome goals included scheduling or completion of a transition focused telehealth appointment or referral/scheduling of an adult cardiology appointment, depending on readiness level. A scheduled appointment (as opposed to attendance) was chosen since appointments were scheduled outside the implementation period of this project. Data collection occurred weekly throughout the implementation period. Eligible patients were determined based on clinic schedule and rate of no-shows. The project team met regularly to encourage adherence to the process change. Completed TRAQ tools appeared directly in REDCap and chart review was performed for all participants to collect demographic data. Transition telehealth appointments, receipt or referrals, and adult cardiology scheduled appointments were confirmed by chart and EHR review.

Patient demographic characteristics were analyzed using quantitative descriptive statistics. Means were calculated for overall TRAQ scores and each of the four domains. Structure goals were reported as a percentage of providers and staff who were trained in the process change. Process and outcome goals were also reported as a percentage. Run charts were created to illustrate rates of adherence to TRAQ tool delivery and patient participation. Run charts were analyzed for common-cause and special-cause variation. All data gathered continue to be used to guide growth and sustainability of the program at the project site and across the organization. The TRAQ tool continues to be available for use with future patients, with QI-PL

having trained clinic NPs on the delivery and scoring of the tool utilizing the QR code and REDCap.

### **Ethics**

Participation was voluntary. Benefits of participation included understanding transition readiness, access to transition focused telehealth appointments, and decreased risk of care discontinuity. Risks were minimal. The TRAQ tool was self-administered through REDCap and all data collection was performed on-site utilizing REDCap. Identified TRAQ scores were only shared with the patient, NPs, primary cardiologist, and the PL. Non-human Subject's Research determination was obtained from the site's Institutional Review Board (IRB) prior to project implementation.

Non-English-speaking patients and those less than 16 years of age were excluded, both vulnerable groups that would benefit from this initiative (Mackie et al., 2022; Schmidt et al., 2020). Adequately translating program materials into multiple languages was outside the project's scope. Patients less than 16 years old have different developmental and transition needs than older adolescent patients, who face a more imminent transition to adult services (Mackie et al., 2022).

### **Results**

Structure goals were achieved in the first week of implementation, including availability of all appropriate materials and completion of provider and staff training. Table 4 summarizes the reach of initial training and education. Table 5 presents a summary of eligible patients seen each week, including no-shows, patients who were approached to participate, and finally, participants. A total of 65 eligible patients were identified. There were 13 no-shows or last-minute cancellations among eligible patients, for a total of 52 eligible patients. A total of 17

patients ( $n=17$ ) participated. Participant demographics are summarized in Table 6. Twelve participants (71%) were between the ages of 16–18 years, with a mean age of 17.9 years. Nine participants (53%) were male and eight (47%) were female; none identified as transgender or non-binary according to review of medical records. Eleven participants (65%) had private insurance. Nine participants (53%) had a CHD diagnosis.

TRAQ scores are summarized in Table 7. Mean overall score was 3.8, eight participants (47%) scored in the 3–4 range. This range indicates progress towards readiness with demonstration of initiation and active participation across behaviors (ETSU, n.d.). Seven participants (41%) scored  $>4$ , indicating readiness for transition. Talking with Providers is the domain with the highest mean score (4.5), with 14 participants (82%) scoring  $>4$ .

Adherence to delivery of the TRAQ tool by staff was high across the implementation period. Figure 4 presents a run chart of staff adherence to the process change, represented by percentage of eligible patients who received introductory materials. In 13 out of 17 weeks 100% of eligible patients were approached to participate; across all 17 weeks of implementation 88% of eligible patients ( $n=46$ ) were approached to participate. In three out of four weeks where adherence was below 100% there were clear explanations, such as expanded eligibility criteria or patients were added to the schedule late.

Participation by 100% of eligible patients was another process goal. Participation rates were erratic. A run chart of patient participation by implementation week is presented in Figure 5. Seventeen patients elected to participate, a response rate of 37%. In weeks one, three, and six patient participation was 100%, but only one eligible patient presented. Weeks 8, 11, 14, and 17 saw the highest volumes of patients. Participation fell below the median in all of these weeks, except week eight. Project team met regularly to discuss methods of increasing patient

participation. A minor incentive to participate was introduced in week four, but participation rates remained inconsistent. The final process goal was review of 100% of TRAQ scores by a provider. This goal was fully met and is illustrated in a run chart in Figure 6.

Outcome goals included scheduling transition focused telehealth appointment or an adult cardiology appointment, as appropriate. Table 8 summarizes these outcomes. All participants were appropriately contacted regarding next steps in transition process. Three participants (18%) scheduled or attended a transition focused telehealth appointment. Four participants (24%) received referral or scheduled an appointment with adult cardiology. Four participants (24%) reported receiving transition education and interventions through another specialty such as oncology or nephrology and did not wish to attend additional transition appointments. Six participants (35%) did not respond to contact attempts.

### **Discussion**

During implementation, 35% of patients 16 years and older received documented transition education or referral, a more than tenfold improvement. Additionally, high rates of adherence by providers and staff to the process change demonstrate the feasibility of implementing these initiatives. While participation rates were inconsistent, this is not surprising given this is a novel initiative for this site. Adolescent healthcare transition is anxiety provoking for patients and families and may take multiple introductions before patients participate (John et al., 2022). The AHA recommends that transition concepts are consistently reinforced; patient and family engagement should be routinely sought and encouraged (John et al., 2022). The time period of implementation limited the possibility of approaching patients multiple times. Continuation of this initiative beyond 17 weeks would regularly incorporate transition discussions into patient care, decreasing hesitation and increasing participation.

TRAQ scores among participants reflected the highest level of readiness in the “Talking with Providers” domain. This domain had the highest mean score of 4.5, with 82% of participants ( $n=14$ ) scoring  $>4$ . This is consistent with other findings from transition literature and may reflect the rapport that develops due to the long-standing relationship between the patient and their primary cardiologist (Gaydos et al., 2020). This trust is often cited as a reason for hesitation to begin the transition process, but it could also be leveraged to encourage engagement and increase autonomy (Heery et al., 2015).

Among participants, 24% ( $n=4$ ) stated their transition was managed by a separate sub-specialty such as hematology/oncology or nephrology and did not wish to attend additional transition appointments. This finding supports the need for multi-disciplinary interventions with inter-specialty collaboration, an issue that is discussed in transition literature (John et al., 2022; Schmidt et al. 2020). Sustainability plans include the creation of a transition coalition with stakeholders from multiple pediatric and adult sub-specialties across the medical center.

This QI initiative did not exclude patients with neurodevelopmental disorders and participants were not specifically screened for these disorders. The rate of neurodevelopmental disorders is higher among patients with CHD and those who have been on cardiopulmonary bypass (John et al., 2022). Patients with these disorders face more challenges in transitioning to adult care and have a higher risk of adverse outcomes. This is a limitation of this project and an issue that warrants careful consideration in the development of comprehensive transition initiatives for this population (John et al., 2022).

Another limitation of this project included unexpected physician staffing challenges limiting the number of eligible patients with a CHD diagnosis. This led to expanded eligibility in week four to include patients with other cardiac diagnoses such as acquired cardiomyopathy,

arrhythmias, and hyperlipidemia. Even with expanded eligibility, the number of eligible patients was lower than anticipated. Most transition literature in cardiology focuses only on patients with CHD, potentially limiting the ability to compare this and previously described initiatives (Everitt et al., 2017; John et al., 2022). Still, literature in other pediatric sub-specialties supports transition interventions for all AYA patients (Schmidt et al., 2020).

### **Conclusions**

This paper presents the successful implementation of a transition readiness assessment in a pediatric cardiology practice with a robust AYA population. The TRAQ tool was utilized to assess transition readiness and identify patterns in readiness across participants. This clinic saw improvement in transition education documentation and appropriate management during the implementation period. Program sustainability was given careful consideration. A tool that can be self-administered by patients or sent out to patients electronically fits seamlessly into workflow.

Assessing transition readiness is only effective as part of a comprehensive transition program (John et al., 2022; Uzark et al., 2020). This QI project also implements transition-focused telehealth appointments and facilitates the development of transition interventions within cardiology and across the institution. Future options for program growth include expansion to younger adolescents and non-English speaking patients, offering transition interventions tailored to patients with neurodevelopmental disorders, and increased collaboration with other pediatric and adult sub-specialties. Each of these elements presents an opportunity for future QI and knowledge translation work.

Patients with cardiac disease now routinely survive into adulthood, a trend that is seen across pediatric specialties (John et al., 2022; Schmidt et al., 2020). These patients require

tailored transition interventions to decrease care discontinuity, improve patient satisfaction, and ensure appropriate resource utilization (Schmidt et al., 2020). Pediatric NPs are well-positioned to lead the healthcare team in developing and implementing these interventions across practice settings.

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**Table 1**

*Evidence Review*

Johnson, K., McBee, M., Reiss, J., Livingood, W., & Wood, D. (2021). TRAQ changes: Improving the measurement of transition readiness by the transition readiness assessment questionnaire. <i>Journal of Pediatric Nursing</i> , 59, 188–195. <a href="https://doi.org/10.1016/j.pedn.2021.04.019">https://doi.org/10.1016/j.pedn.2021.04.019</a>					<b>Level and Quality</b> Level III Quality: Good
<b>Purpose/ Hypothesis</b>	<b>Type of Evidence Research Design</b>	<b>Sample – Population, Size, Setting</b>	<b>Intervention/Procedures</b>	<b>Primary Outcome/Measures</b>	<b>Results/Conclusions</b>
To improve the precision and overall performance of the Transition Readiness Assessment Questionnaire (TRAQ) across all levels of transition readiness. Previous versions of the TRAQ performed better at lower levels of readiness.	Research  Analysis with Item Response Theory (IRT) to refine TRAQ, subsequent pilot of refined TRAQ 6.0	<b>Sampling Technique:</b> convenience  Stage 1: analysis of completed surveys. Convenience sample. Selected <b>506 surveys</b> by adolescents aged 16 and up, from total <b>527 surveys</b> completed by adolescents aged 14 years and older. Stage 2: pilot of new TRAQ. <b>386</b> Adolescent and young adult (AYA) patients aged 16-24 years. 274 were college students, the rest juniors and seniors in high school.  Group Homogeneity: Pilot group (n= 386) was 54% female and 87% white, mean age 20 years	IRT analysis of completed surveys to measure difficulty and discrimination of assessment items. From analysis, low discrimination items were eliminated, and new items added. New items were peer-reviewed by two separate transition and adolescent medicine experts and evaluated by 16 AYA patients aged 16-22 yrs. Refined TRAQ piloted on 386 AYA individuals- 274 college students completed online, the rest in high school and completed paper surveys.	<b>Dependent Variable:</b> goodness of fit of model to the data.  <b>Measures:</b> Assessment of model fit using chi-square statistic, RMSEA, Tucker-Lewis index (TLI), and comparative fit index (CFI).	<b>Statistical Methods/Results:</b> Final 20 item refined TRAQ had good to excellent model fit to the data. $\chi^2(164) = 887.239, p < .001$ CFI = 0.943 TLI = 0.93 RMSEA = 0.0942 (90% CI: 0.090, 0.114) WRMR = 1.111 No items were problematic, and all were required for measurement precision. <b>Clinical significance/conclusions:</b> This result is a TRAQ that has an increased level of difficulty, meaning it discriminates levels of transition readiness across all stages of transition, where previous version was less precise in advanced stages of readiness. Overall improved internal reliability. Refined TRAQ is an improved method of measuring AYA transition readiness.

<p>Mackie, A. S., Rempel, G. R., Kovacs, A. H., Kaufman, M., Rankin, K. N., Jelen, A., Yaskina, M., Sananes, R., Oechslin, E., Dragieva, D., Mustafa, S., Williams, E., Schuh, M., Manlhiot, C., Anthony, S. J., Magill-Evans, J., Nicholas, D., &amp; McCrindle, B. W. (2018). Transition intervention for adolescents with congenital heart disease. <i>Journal of the American College of Cardiology</i>, 71(16), 1768–1777.  <a href="https://doi.org/10.1016/j.jacc.2018.02.043">https://doi.org/10.1016/j.jacc.2018.02.043</a></p>					<p><b>Level and Quality</b>                  Level I                  Quality: Good</p>
Purpose/ Hypothesis	Type of Evidence Research Design	Sample – Population, Size, Setting	Intervention/Procedures	Primary Outcome/Measures	Results/Conclusions
<p>Will a nurse-led transition intervention have an effect on care discontinuity between pediatric and adult care in adolescents with congenital heart disease (CHD)?</p>	<p>Research                  A cluster randomized clinical trial. With the type of intervention, the participants in the program could not be blinded. Those receiving usual care were unaware of the intervention group. All participants were unaware of outcomes.</p>	<p><b>Sampling Technique:</b> Convenience sample from hospital/clinics of author affiliation.  <b># Eligible:</b> 173 16–17-year old’s with previously defined moderate or complex CHD (heart transplant patients and those with reading level &lt;6<sup>th</sup> grade per parent were excluded).  <b># Accepted:</b> 125, 121 analyzed  <b># Control:</b> n=63 (1 withdrew)  <b># Intervention:</b> n=58 (3 withdrew)  <b>Power analysis:</b> 120 patients (60 per group) required for 80+% power, alpha = 0.05. Total patients met, 3 withdrew from intervention group so n=58, not 60  <b>Group Homogeneity:</b> Control and intervention groups largely homogenous based on Table 1. Slightly more moderate CHD in Usual care group (49 vs. 38).</p>	<p><b>Control:</b> Usual care, no formal transition plan in place at either site. When time to transfer care patient receives written information on their diagnosis and history and suggested timeline of follow-up with ACHD provider.  <b>Intervention:</b> Participants in transition intervention group received two one-on-one sessions with an adolescent cardiology RN. Sessions were individualized with a focus on education and self-management.  <b>Intervention fidelity:</b> Team (including study RN’s) were educated by lead investigator at an in-person meeting. Sample intervention sessions were videotaped and study RN’s role-played interventions during training. Intervention session were audio recorded with permission and these recordings were reviewed. All nursing interventions were logged, and logs were reviewed weekly.</p>	<p><b>Dependent Variable:</b>                  Primary: excess time between pediatric and adult CHD care                  Secondary: Change in CHD knowledge score, change in transition readiness score, incidence of cardiac re-intervention  <b>Measures:</b>  <b>Primary:</b> time in months between pediatric and adult visits minus the recommended interval (recommended by cardiologist at final pediatric visit).  <b>Secondary:</b> knowledge of CHD scores assessed with MyHeart scoring tool (at baseline, 1, 6, 12, and 18 months). MyHeart consists of 8 items and was developed in a previous version of this study. Transition readiness was assessed with the Transition Readiness Assessment Questionnaire (TRAQ)-at baseline, 1, 6, 12, and 18 months. TRAQ is best-validated tool availability for assessing transition</p>	<p><b>Statistical Methods/ Results:</b>  <b>Primary:</b> Cox regression. Median excess time 7.0 months in usual care vs. 2.0 months in intervention group. In intervention group 68% were seen within 3 months of recommended time vs. 51% in usual care group (p=0.059).  <b>Secondary:</b> Linear mixed models adjusted for cluster randomization. MyHeart scores were similar at baseline and higher in intervention group at 1, 6, 12, and 18 months (p&lt;0.001). TRAQ scores were also similar at baseline between groups and improved in both groups at 1, 6, 12, and 18 months but showed more improvement in intervention group (p=0.03).  <b>Clinical Significance/Conclusions:</b>                  The significance of the reduction in delay is unknown. These interventions were reproducible at other institutions. Structured transition programs are effective at reducing care delays and improving TRAQ scores in older adolescents (age 16-17 years) with CHD.</p>

				readiness. Incidence of cardiac re-intervention was assessed at 12 and 24 post-enrollment.	
Parfeniuk, S., Petrovic, K., MacIsaac, P., Cook, K. A., & Rempel, G. R. (2020). Transition readiness measures for adolescents and young adults with chronic health conditions: A systematic review. <i>Journal of Transition Medicine</i> , 2(1). <a href="https://doi.org/10.1515/jtm-2020-0020">https://doi.org/10.1515/jtm-2020-0020</a>					<b>Level and Quality</b> Level III Quality: Good
<b>Purpose/ Hypothesis</b>	<b>Type of Evidence Research Design</b>	<b>Sample – Population, Size, Setting</b>	<b>Intervention/Procedures</b>	<b>Primary Outcome/Measures</b>	<b>Results/Conclusions</b>
Identify a superior evidence-based tool for transition readiness assessment as well recommend best practices surrounding AYA healthcare transition (HCT) readiness measurement.	Systematic Review Completed by a panel of advanced practice nurses at Athabasca University in Alberta, Canada.  Evaluated 19 tools, <b>Cohen criteria</b> used to evaluate the quality of each tool included in the SR.	<b>Search Strategy:</b> Literature from January 2014-March 2018 (dates selected due to previous systematic review published in 2014). <b>Databases searched:</b> PubMed, CINAHL, Google Scholar, Athabasca University Library’s Discover <b>Search Terms:</b> Terms were predetermined and related to transition concepts, chronic health condition concepts, survey/ questionnaire concepts. <b>Inclusion criteria:</b> Published in peer-reviewed journal, developed/discussed/ assessed transition readiness measures for patients aged 11-25 years, discussion of psychometric properties of the measure. <b>Exclusion criteria:</b> dissertations, reports, commentaries, reviews and abstracts, articles not in English or translated into English.	48 articles were retained for the final systematic review, covering 19 tools for assessment of transition readiness in AYA patients. <b><u>Tools include (not limited to):</u></b> -TRAQ 4.0/5.0 (discussed/used in 17 studies/articles) -STARx, (discussed/used in 6 studies/articles) -UNC TRxANSITION (discussed/used in 4 studies/articles) -Transition-Q (discussed/used in 2 studies/articles) Included both disease-specific and disease-neutral tools. All but one of the tools is self-administered by AYA patient. Twelve tools used Likert scale.  <a href="#">Intervention fidelity</a> (describe the protocol): N/A, systematic review (SR)	Outcomes of included studies vary, and some were non-experimental research designs. Each study discussed the psychometrics of an AYA HCT readiness assessment tool. Each of the 19 tools was evaluated according to the Cohen criteria.	<b><u>Statistical Methods/Results:</u></b> TRAQ is the most well-validated measure currently available. It is a disease-neutral and grounded in theory. <b><u>Clinical significance/conclusions:</u></b> Makes best practice recommendations, including transition readiness measures should be based on a theoretical framework, readiness assessment should be repeated over time, multiple stakeholders should be involved in the transition process. Finally, utilization of the TRAQ to assess HCT readiness is the final best practice recommendation.

		<p><b>Screening:</b> 1851 articles identified; 164 duplicates removed. 1617 excluded following screening of titles and abstracts by 2 reviewers. 32 excluded upon review of full text.</p> <p><b>PRISMA flow diagram included</b></p>			
<p>Schmidt, A., Ilango, S. M., McManus, M. A., Rogers, K. K., &amp; White, P. H. (2020). Outcomes of pediatric to adult health care transition interventions: An updated systematic review. <i>Journal of Pediatric Nursing</i>, 51, 92–107. <a href="https://doi.org/10.1016/j.pedn.2020.01.002">https://doi.org/10.1016/j.pedn.2020.01.002</a></p>					<p><b>Level and Quality</b> Level III Quality: High</p>
Purpose/ Hypothesis	Type of Evidence Research Design	Sample – Population, Size, Setting	Intervention/Procedures	Primary Outcome/Measures	Results/Conclusions
<p>An updated systematic review (SR) that builds on previous SR by Gabriel et al. (2017). Explores which HCT interventions have an impact on three separate domains. These include population health, the patient healthcare experience, and healthcare cost and appropriate utilization.</p>	<p>Systematic Review conducted by a panel with expertise in public health and adolescent health. SR design is similar to one used in a previous SR. This SR adjusts study selection criteria and performs analyses to compare the studies to the previous SR (Gabriel et al., 2017). <b>Quality:</b> Study quality was assessed according to the EPHPP Quality Assessment Tool.</p>	<p><b>Search Strategy:</b> Relevant HCT literature published May 2016-December 2018 (not included in Gabriel et al., 2017) <b>Databases searched:</b> Scopus, Web of Science, PubMed, CINAHL, Ovid Medicine (Figure 1) <b>Search terms included (but not limited to):</b> adolescent, young adult, teen, transition, transfer, transition to adult care, transferring to adult care, cost OR health care costs, continuity of pediatric care (Figure 1 of study) <b>Screening and exclusion:</b> 2050 articles screened, 61 read in full, 19 retained for SR. 1,989 were excluded initially due to irrelevant title or abstract. 42 of full text</p>	<p><b>Controls:</b> Control groups included those who received usual care, groups prior to receiving transition interventions, groups at centers prior to implementation of transition programs/interventions. <b>Intervention:</b> Interventions in retained studies included a variety of transition interventions (including but not limited to care coordination, transition planning, transfer assistance, adult care integration). Components of each intervention in each study listed in Table 4.</p>	<p><b>Dependent Variable:</b> Population health (adherence to monitoring and measures, health and quality-of-life as reported by patients, mortality), patient experience (satisfaction and barriers), utilization/cost of care (processes, utilization, cost). Positive outcomes for specific diseases such as decrease in HbA1c in diabetes or survival post-transplant (Table 3). <b>Measures:</b> varied by study-questionnaires, disease-specific measures, adherence to regimens and monitoring.</p>	<p><b>Statistical Methods/Results:</b> Further comparison of HCT interventions and comparison with previous SR (Gabriel et al., 2017). 16 of the 19 articles reported statistically significant positive outcomes related to the implementation of structured HCT interventions. More studies used a cohort design than RCT, but studies were stronger than those included in previous SR (Gabriel et al., 2017). <b>Conclusions:</b> This SR provides further evidence that structured HCT interventions can improve patient outcomes and provide healthcare value.</p>

		<p>reviewed articles were excluded due to lack of proper intervention/ evaluation/ transfer or qualitative nature, did not report sample size (Figure 2 in study).</p> <p><b>Eligible Studies:</b> RCT’s, pre- and post- intervention comparisons, intervention and non-intervention comparisons (prospective/retrospective cohort studies)</p> <p><b>PRISMA</b> included to show decision-making regarding inclusion/ exclusion/screening</p>			
<p>Stewart, K. T., Chahal, N., Kovacs, A. H., Manlhiot, C., Jelen, A., Collins, T., &amp; McCrindle, B. W. (2017). Readiness for transition to adult health care for young adolescents with congenital heart disease. <i>Pediatric Cardiology</i>, 38(4), 778–786. <a href="https://doi.org/10.1007/s00246-017-1580-2">https://doi.org/10.1007/s00246-017-1580-2</a></p>					<p><b>Level and Quality</b> Level: III Quality: Good</p>
Purpose/ Hypothesis	Type of Evidence Research Design	Sample – Population, Size, Setting	Intervention/Procedures	Primary Outcome/Measures	Results/Conclusions
<p>What medical, patient, and parent factors are associated with transition readiness in adolescents ages 12-15 with CHD? Evaluation of transition readiness, medical knowledge, and self-efficacy in adolescents aged 12-15 with CHD.</p>	<p>Research Quantitative cross-sectional</p>	<p><b>Sampling Technique:</b> Convenience sample.</p> <p># eligible: 543 (surveys sent to all eligible) # responded: 100 # accepted: 82 (18 excluded for not meeting all criteria)</p> <p>Inclusion: 12-15 years with moderate to complex CHD. Exclusion: heart transplant, language barriers, neurocognitive impairment</p> <p>Group Homogeneity: 44%</p>	<p><b>Intervention:</b> completed demographics questionnaire, TRAQ, MyHeart medical knowledge questionnaire, children’s uncertainty in illness scale (CUIS), and a general self-efficacy scale.</p> <p><a href="#">Intervention fidelity</a> (describe the protocol):</p>	<p><b>Dependent Variable:</b> Factors associated with transition readiness. Level of transition readiness, knowledge of medical condition, level of self-efficacy and illness uncertainty.</p> <p><b>Measures:</b> Transition readiness measured with TRAQ- a disease-neutral, validated tool that has been used with CHD patients. MyHeart medical knowledge was developed for previous CHD transition</p>	<p><b>Statistical Methods/Results:</b> 24% of patients remembered discussing HCT with a provider. Older patients more likely to have discussed [odds ratio 1.838, 95% CI + 1.184, +2.854, p=0.007) Mean TRAQ score 2.91 +/- 0.82. Mean MyHeart score 71 +/- 20%, increased with increasing age. Mean CUIS score 32.9 +/- 8.5 Mean GSE score 3.0 +/- 0.6 CUIS and GSE scores not associated with age.</p>

		male, mean age 13.6 years +/- 1.3 years. 29% had septal defects. 73% had undergone cardiac surgery, 59% cardiac catheterization.		studies. Patients get a % correct with correct answers taken from their chart. Self-Efficacy measured with general self-efficacy scale (GSE). A validated tool with 10 items. Illness Uncertainty assessed with children's uncertainty in illness scale (CUIS). No evidence of validity provided for CUIS.	Figure 1 and Table 2 contain data related to factors associated with TRAQ score. increase in TRAQ total score was significantly correlated with -age (EST: +0.17, 95%CI +0.03, +0.31, p=0.02) -patient medical condition knowledge (EST +0.91, 95%CI +0.04, +1.79, p=0.04) -self-efficacy (EST: +0.54, 95%CI +0.26, +0.83, p<0.001) <b>Clinical significance/conclusions:</b> TRAQ scores are significantly correlated with several patient factors. TRAQ scores increase with increasing knowledge surrounding medical condition. Transition readiness and self-management are also positively correlated with parental knowledge and involvement.
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. <i>The Journal of Pediatrics</i> , 167(6), 1233–1238. <a href="https://doi.org/10.1016/j.jpeds.2015.07.043">https://doi.org/10.1016/j.jpeds.2015.07.043</a>					<b>Level and Quality</b> Level III Quality: Good
<b>Purpose/ Hypothesis</b>	<b>Type of Evidence Research Design</b>	<b>Sample – Population, Size, Setting</b>	<b>Intervention/Procedures</b>	<b>Primary Outcome/Measures</b>	<b>Results/Conclusions</b>
Examine transition readiness in AYA patients aged 13-25 years with CHD or heart transplant. Does transition readiness assessment effect information seeking	Research  Cross-Sectional study	Sampling Technique: convenience # eligible: Not stated. Eligibility criteria: 13-25 years, Diagnosis of CHD or heart transplant # accepted: n=164 Excluded if experiencing an acute problem at that visit or	Completion of the Transition Readiness Assessment and Pediatric Quality of Life Inventory. Completed on an electronic tablet over the internet. Completion of assessments performed during a routine clinic visit.	<b>Dependent Variable:</b> Quality of life scores, perceived knowledge deficits as they are correlated to transition readiness measures.  <b>Measures:</b> Transition Readiness was assessed	<b>Statistical Methods/Results:</b> Perceived knowledge deficits in all ages were 25.7% +/- 16.8% (range 0-75%), with patients under 18 years having higher rates of perceived knowledge deficits. Health insurance, pregnancy, contraception, how to contact

<p>behaviors or quality of life in this population?</p>		<p>if significant neurocognitive impairment</p> <p>Group Homogeneity: Median age 18.1 years, 59% male, 90% white, 18.3% single ventricle patients, 4.3% heart transplant, 40.2% taking medications</p>	<p>Performed analyses to correlate transition readiness scores with demographic information. Analysis of relationship between transition readiness assessment scores and psychosocial quality of life scores.</p>	<p>with a newly developed tool they were field testing that used a 5-point Likert scale. Included aspects of other transition assessments modified for this population. Internal consistency and reliability had been established for most items. Confirmation of expected relationships supports validity. The PedsQL 4.0 was used to assess quality of life and has demonstrated reliability and validity.</p>	<p>the doctor, and concerning symptoms were the areas with largest knowledge deficits. Higher Peds QL Psychosocial functioning scores were associated with lower perceived knowledge deficits.</p> <p><b>Clinical significance/conclusions:</b> AYA patients with CHD have a high rate of knowledge deficits surrounding HCT. Those with higher rates of knowledge deficits have lower scores on quality-of-life measures and report decreased self-management skills and self-efficacy. The routine assessment of transition readiness is recommended to help identify knowledge deficits, direct teaching, and improve quality of life.</p>
<p>Uzark, K., Yu, S., Lowery, R., Afton, K., Yetman, A. T., Cramer, J., Rudd, N., Cohen, S., Gongwer, R., &amp; Gurvitz, M. (2020). Transition readiness in teens and young adults with congenital heart disease: Can we make a difference? <i>The Journal of Pediatrics</i>, 221, 201–206.e1. <a href="https://doi.org/10.1016/j.jpeds.2020.02.040">https://doi.org/10.1016/j.jpeds.2020.02.040</a></p>					<p><b>Level and Quality</b> Level: III Quality: Good</p>
<p><b>Purpose/ Hypothesis</b></p>	<p><b>Type of Evidence Research Design</b></p>	<p><b>Sample – Population, Size, Setting</b></p>	<p><b>Intervention/Procedures</b></p>	<p><b>Primary Outcome/Measures</b></p>	<p><b>Results/Conclusions</b></p>
<p>How do transition readiness scores change over time? What factors affect transition readiness scores, quality of life, and healthcare utilization rates in AYA patients with CHD? Builds on previous research by Uzark et al., 2015.</p>	<p>Research Multi-center prospective cohort study</p>	<p>Sampling Technique: convenience sample from institutions of author affiliation- 4 sites, initial n=409, age 13-25 years At one year n=356 (87% of initial) age 14-27 years Difference in n is accounted for. Diagnosis of CHD or heart transplant</p>	<p>Completion of Transition Readiness Assessment and Pediatric Quality of Life Inventory (PedsQL). Surveys completed on an electronic tablet. Completed at a routine visit and then a subsequent routine follow-up visit. Analyses were performed for correlations between transition readiness scores and</p>	<p><b>Dependent Variable:</b> change in transition readiness scores, correlation with PedsQL scores.</p> <p><b>Measures:</b> This is as above in Uzark et al., 2015. Transition Readiness was assessed with the previously developed tool that used a 5-point Likert scale. Initial psychometrics demonstrate</p>	<p><b>Statistical Results</b> Perceived knowledge deficits were reported initially in 24.7% of patients but decreased to 18% at follow-up (p&lt;.0001). Those who reported fewer knowledge deficits report receiving education on their condition. Self-efficacy (71.4 +/- 17.0 to 76.7 +/- 18.2 [p= .0004]) and self-management scores (47.9</p>

		<p>Excluded if that visit was for an acute problem, significant neurocognitive impairment.</p> <p>Median age (initial) 18.7 years, 57.2% &gt; 18 years, 32.8% female, 89% white, 51.8% taking medication.</p>	<p>demographic information, quality of life index items.</p>	<p>“acceptable internal consistency reliability, construct validity, and responsiveness” (p. 74). The PedsQL 4.0 was used to assess quality of life and has demonstrated reliability and validity.</p>	<p>+/- 18.4 to 52.0 +/- 20.7 [p=.0004]) improved at follow-up especially in those patients who reported receiving transition education. (Table III and Table IV). A decrease in perceived knowledge deficits was associated with increased psychosocial quality of life scores (p=.03).  <b>Clinical significance/ conclusions:</b> Adds further evidence that there are many knowledge deficits pertaining to HCT in AYA patients with CHD. These deficits affect quality of life and levels of self-management. The assessment of transition readiness is essential to identify these deficits and even in the absence of structured intervention the readiness assessment can prompt further discussion and individualized teaching.</p>
<p>Wood, D. L., Sawicki, G. S., Miller, M., Smotherman, C., Lukens-Bull, K., Livingood, W. C., Ferris, M., &amp; Kraemer, D. F. (2014). The transition readiness assessment questionnaire (TRAQ): Its factor structure, reliability, and validity. <i>Academic Pediatrics, 14</i>(4), 415–422.  <a href="https://doi.org/10.1016/j.acap.2014.03.008">https://doi.org/10.1016/j.acap.2014.03.008</a></p>					<p><b>Level and Quality</b>                      Level: III                      Quality: High</p>
<p><b>Purpose/ Hypothesis</b></p>	<p><b>Type of Evidence Research Design</b></p>	<p><b>Sample – Population, Size, Setting</b></p>	<p><b>Intervention/Procedures</b></p>	<p><b>Primary Outcome/Measures</b></p>	<p><b>Results/Conclusions</b></p>
<p>Further analysis of the internal reliability and criterion validity of the TRAQ scale. Gain knowledge related to the</p>	<p>Research  3 stages of data collection and analysis. 1) Exploratory Factor Analysis</p>	<p>Sampling Technique: Convenience from three clinic sites in FL, MA, and NC Stage 1) n=269 (36 had missing responses</p>	<p>Surveys filled out by a total of 526 AYA individuals with special healthcare needs. Stage 1) multiple rounds of exploratory factor analysis with elimination of items.</p>	<p>DV: Internal reliability and criterion validity of TRAQ scale. Stage 1 EFA done with orthogonal orthomax rotation</p>	<p>Extensive statistical results available- see Table 2, Table 3, Table 4, SAS documentation supplement. EFA lead to removal of items for a total 20 item questionnaire.</p>

<p>constructs involved in HCT skills and readiness assessment.</p>	<p>2) Confirmatory Factor Analysis 3) Reliability and Criterion Validity testing.</p>	<p>Stage 2) n=221 (43 had missing responses) Stage 3) n=526 (n=447 without missing responses) [stage 3 sample was combination of 1 and 2] Age 14-21 years with special healthcare needs (included a variety of conditions) Group Homogeneity: 83.1% &gt;= 18 years 34.8% male, 39.5% female, 25.7% declined to answer 42.6% white, 34.4% black, 26% with private insurance, 60% with public insurance</p>	<p>Stage 2) Confirmatory Factor Analysis until all TRAQ items demonstrated goodness of fit with a structural equation model. Stage 3) Reliability and criterion validity testing. Reliability= Cronbach's alpha for entire scale and all subscales. Validity= Wilcoxon rank sum test and Kruskal-Wallis ANOVA. Control</p>	<p>Stage 2 CFA goodness-of-fit testing done with root mean square error approximation (RMSEA), goodness-of-fit index (GFI), and Betler comparative index. Stage 3 Wilcoxon rank sum and Kruskal-Wallis ANOVA  Statistical analyses done with PROC CALIS in SAS version 9.3 for Windows. Complete SAS documentation supplement available.</p>	<p>CFA: P value for goodness of fit =0.15, RMSEA (95% CI) = 0.0268 (0, 0.0463), probability of close fit p value=0.098. GFI=0.92, Bentler comparative fit index = 0.992. Cronbach's alpha for overall scale (pooled sample) =0.937, 4 (of 5) subscales had Cronbach's alpha &gt;0.70 <b><u>Clinical significance/conclusions:</u></b> "TRAQ demonstrates good internal reliability and criterion validity" (p. 420).</p>
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**Table 2**

*Evidence Synthesis*

Category (Level Type)	Total Number of Sources/Level	Overall Quality Rating	Synthesis of Findings
Level I - Experimental study · Randomized Controlled Trial (RCT) · Systematic review of RCTs with or without meta-analysis	1 Cluster-randomized clinical trial	B- Good	Mackie et al. (2018) present a cluster randomized clinical trial that supports the use of structured transition programs in adolescents aged 16-17 years with congenital heart disease (CHD). The investigators demonstrate that a structured transition intervention reduced delays in care compared to usual care. Their transition program also led to improvement in TRAQ (transition readiness) and MyHeart (medical condition knowledge) scores.
Level II · Quasi-experimental studies · Systematic review of a combination of RCTs and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis	0		
Level III · Non-experimental study · Systematic review of a combination of RCTs, quasi-experimental, and non-experimental studies, or non-experimental studies only, with or without meta-analysis · Qualitative study or systematic review of qualitative studies with or without meta-synthesis	7 2 systematic reviews of experimental and non-experimental studies. 2 research-based analyses of TRAQ tool 2 quantitative cross-sectional 1 prospective cohort	B- Good	Schmidt et al. (2020) conducted a systematic review that supports the efficacy and value of structured healthcare transition (HCT) interventions for adolescent and young adult (AYA) patients with a variety of diagnoses. A prospective cohort study by Uzark et al. (2020) and quantitative cross-sectional studies by Uzark et al. (2015) and Stewart et al. (2017) demonstrate the existence of knowledge deficits among AYA patients with CHD, that transition readiness scores can improve with education and are correlated with other patient factors and support the routine assessment of transition readiness as part of a structured HCT program. Research-based analyses by Wood et al. (2014) and Johnson et al. (2021) demonstrate the reliability and validity of the Transition Readiness Assessment Questionnaire (TRAQ) scale in AYA patients with special healthcare needs. A systematic review by Parfeniuk et al. (2020) demonstrates the superior validity of the TRAQ scale when compared to other transition assessment tools and recommends use of the TRAQ tool as a best practice guideline.
Level IV · Opinion of respected authorities and/or reports of nationally recognized expert committees/consensus panels based on scientific evidence	0		
Level V · Evidence obtained from literature reviews, quality improvement, program evaluation, financial evaluation, or case reports · Opinion of nationally	0		

<p>recognized expert(s) based on experiential evidence</p>			
<p>Recommendations Based on Evidence Synthesis: This body of evidence supports the efficacy of structured HCT interventions for AYA patients, including the importance of assessing transition readiness as part of these interventions. It supports use of the TRAQ scale as a validated measure of transition readiness in these patients. There is good and consistent evidence to support the implementation of the TRAQ to assess transition readiness among pediatric cardiology patients ages 16 years and older.</p>			

**Table 3**

*Project Goals*

<b>Structure Goals</b>	<b>Process Goals</b>	<b>Outcome Goals</b>
<p>By September 2, 2022, 100% of pediatric cardiology clinic staff (MA, RN) will receive training on TRAQ form, patient eligibility, and process for handing out/collecting survey.</p>	<p>By December 16, 2022, 100% of eligible patients seen for follow-up appointment will be approached to participate and receive TRAQ tool.</p>	<p>By December 16, 2022, 100% of patients with TRAQ score &lt;4 will have scheduled or completed a transition focused NP telehealth appointment.</p>
<p>By September 2, 2022, 100% of pediatric cardiology physicians and NPs will receive training on TRAQ form including process change and reviewing of scores.</p>	<p>By December 16, 2022, 100% of eligible patients approached will participate.</p>	<p>By December 16, 2022, 100% of patients with TRAQ score &gt;4 will have scheduled or completed an adult congenital heart disease appointment.</p>
<p>By September 2, 2022, the TRAQ forms will be available in the pediatric cardiology clinic, as well as designated place to collect completed forms following patient appointment.</p>	<p>By December 16, 2022, 100% of completed TRAQ forms will have documented review by pediatric cardiology provider.</p>	

**Table 4***Training and Education of Staff*

Role	# of staff in that role	# of staff who received training	% who received training
Pediatric Cardiologists	6	6	100%
Pediatric Cardiology Nurse Practitioners	2	2	100%
Regular Clinic staff (Registered Nurse, Medical Assistant, administrative)	5	5	100%
Regular pediatric cardiac sonographers	9	9	100%
<b>Total</b>	<b>22</b>	<b>22</b>	<b>100%</b>

*Note.* Training provided in-person, virtually, and via email.

**Table 5**

*Eligible Patients and Participants by Implementation Week*

Implementation Week	Eligible patients scheduled	Eligible patients seen	No-show/last-minute cancellation amongst eligible patients	Eligible patients approached	% of eligible patients approached	Participants	% of eligible patients seen who participate
1	2	1	1	1	100%	1	100%
2	2	2	0	2	100%	0	0%
3	1	1	0	1	100%	1	100%
4	3	3	0	2	67%	0	0%
5	4	4	0	4	100%	3	75%
6	2	1	1	1	100%	1	100%
7	2	1	1	1	100%	0	0%
8	10	8	2	8	100%	4	50%
9	2	1	1	1	100%	0	0%
10	3	2	1	2	100%	0	0%
11	7	7	0	6	86%	1	17%
12	3	3	0	3	100%	2	67%
13	2	1	1	1	100%	0	0%
14	6	6	0	4	67%	0	0%
15	3	3	0	3	100%	1	33%
16	5	2	3	2	100%	2	100%
17	8	6	2	4	67%	1	25%
<b>Total</b>	<b>65</b>	<b>52</b>	<b>13</b>	<b>46</b>	<b>88%</b>	<b>17</b>	<b>37%</b>

**Table 6**

*Demographic Characteristics of Participants (n=17)*

Characteristics	n	%	Range	Mean
Age in years			16-21	17.9 years
16-18	12	71%		
19-21	4	24%		
21+	1	6%		
Gender				
Male	9	53%		
Female	8	47%		
Insurance Status				
Private	11	65%		
Public	6	35%		
Diagnosis				
CHD	9	53%		
Non-CHD	8	47%		

*Note.* Percentages may not equal 100% due to rounding.

**Table 7**

*Participant TRAQ Scores (n=17)*

Domain/Score	n	%	Range	Mean
Overall TRAQ Score			2.0-4.9	3.8
<2	0	0%		
2-3	2	12%		
3-4	8	47%		
>4	7	41%		
Managing Medications			1.4-5.0	3.3
<2	3	18%		
2-3	4	24%		
3-4	4	24%		
>4	6	35%		
Appointment Keeping			1.0-5.0	3.7
<2	2	12%		
2-3	1	6%		
3-4	6	35%		
>4	8	47%		
Tracking Health Issues			2.0-5.0	3.9
<2	0	0%		
2-3	2	12%		
3-4	6	35%		
>4	9	53%		
Talking with Providers			2.2-5.0	4.5
<2	0	0%		
2-3	1	6%		
3-4	2	12%		
>4	14	82%		

*Note.* TRAQ scores <2 indicate not yet started or no interest in behaviors, 2-3 indicate interest and some initiation, 3-4 demonstrate initiation and some active participation, 4+ demonstrates active participation consistently and readiness for transition (ETSU, n.d.). Percentages may not equal 100% due to rounding.

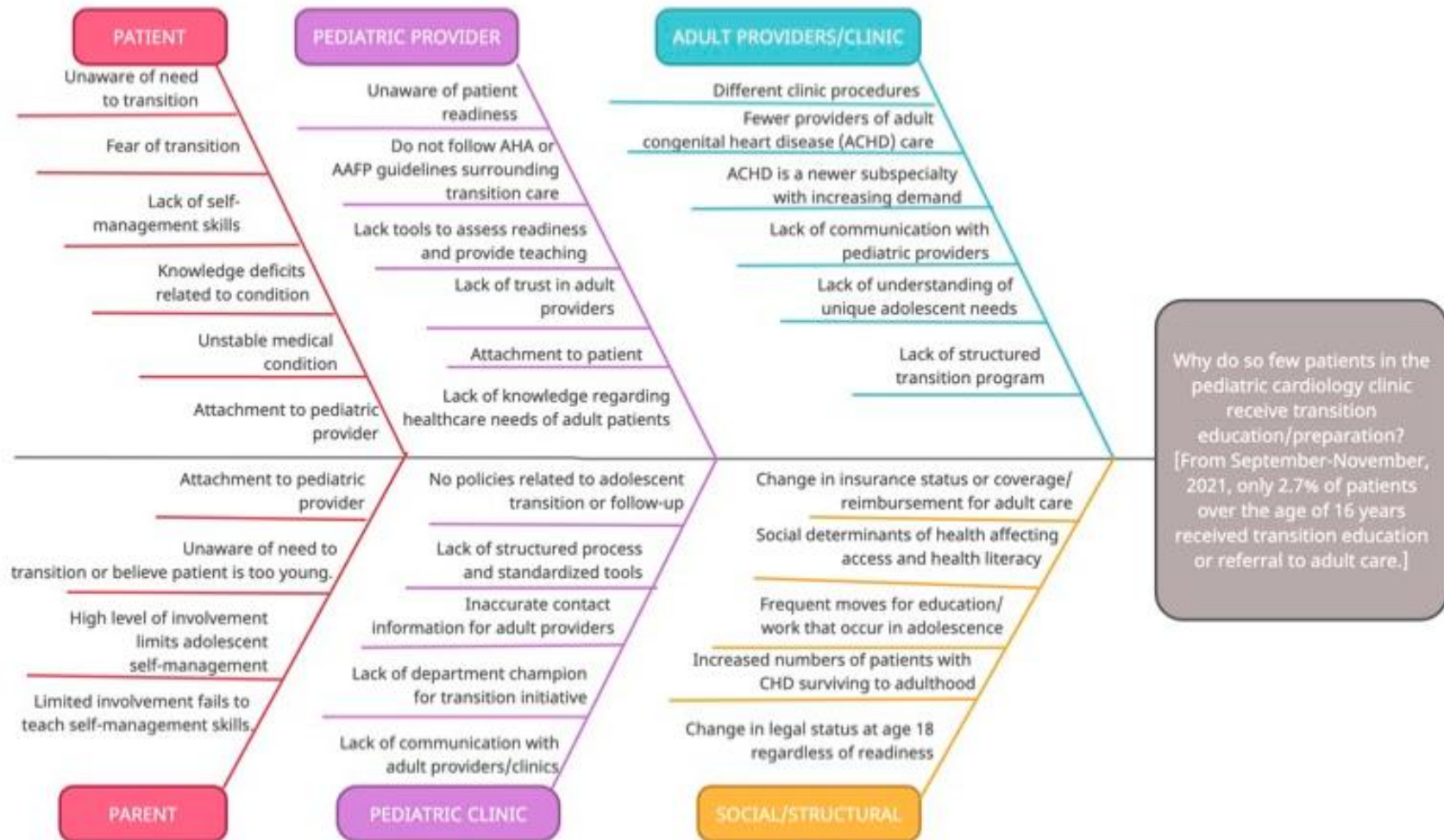
**Table 8***Outcome Goals: Participant Follow-Up (n=17)*

	n	%
Scheduled or Attended Transition Focused Telehealth Appointment	3	18%
Scheduled Adult Cardiology Appointment	4	24%
Healthcare Transition Managed by Outside Specialty	4	24%
Team Attempted Follow-Up, No Patient Response	6	35%

*Note.* Percentages may not equal 100% due to rounding.

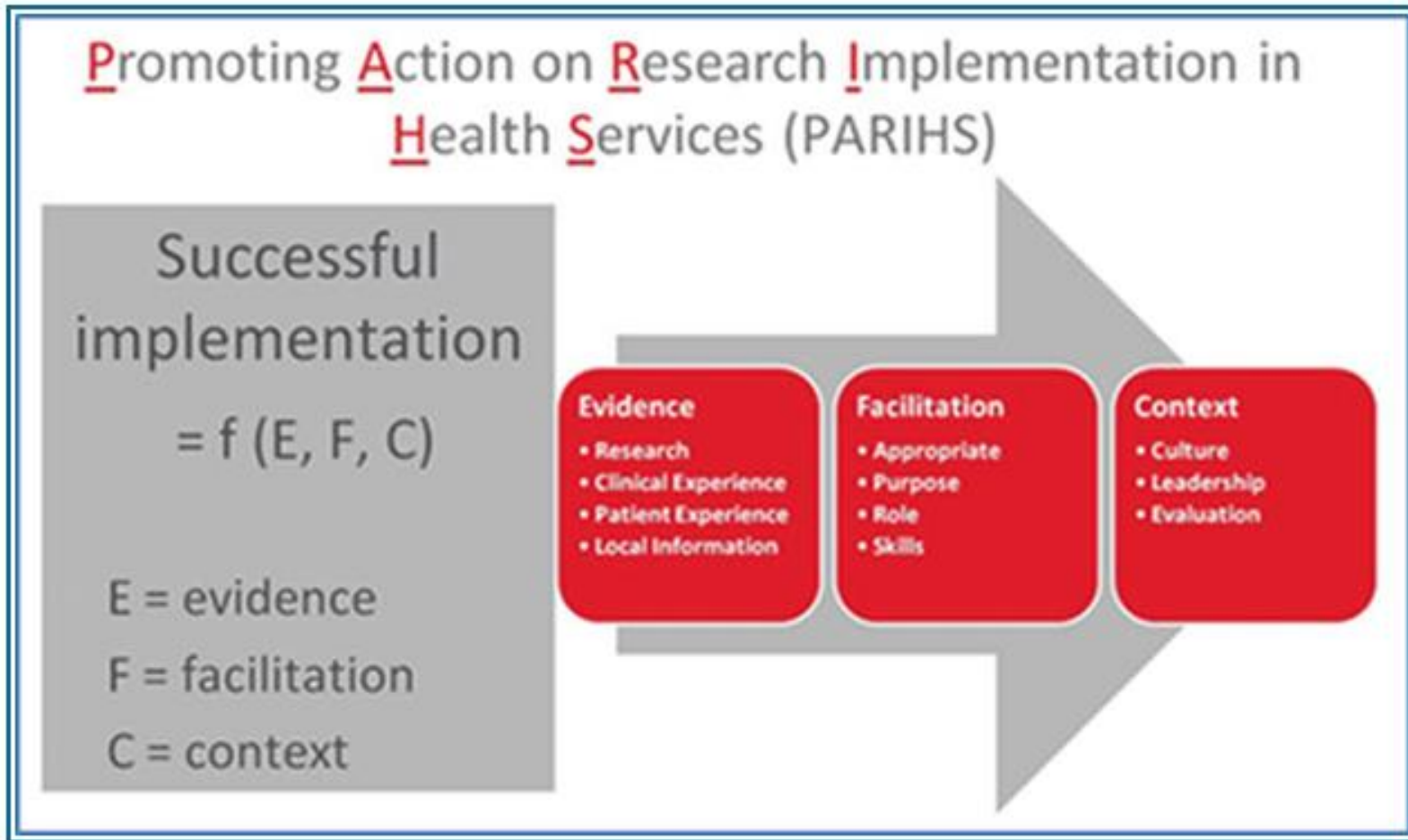
**Figure 1**

*Fishbone Diagram for Root Cause Analysis*



**Figure 2**

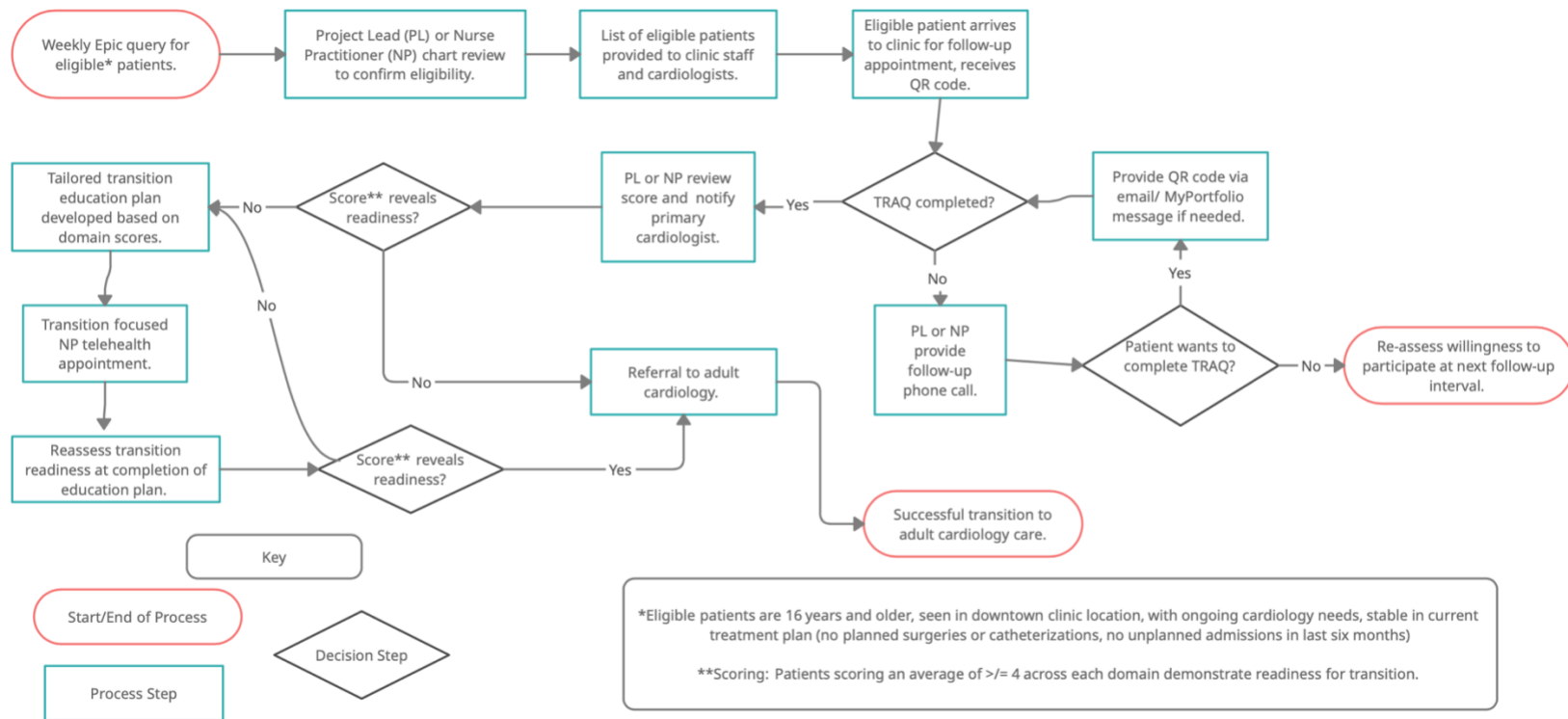
*Promoting Action on Research Implementation in Health Services (PARIHS) Framework*



Kitson et al., 2008

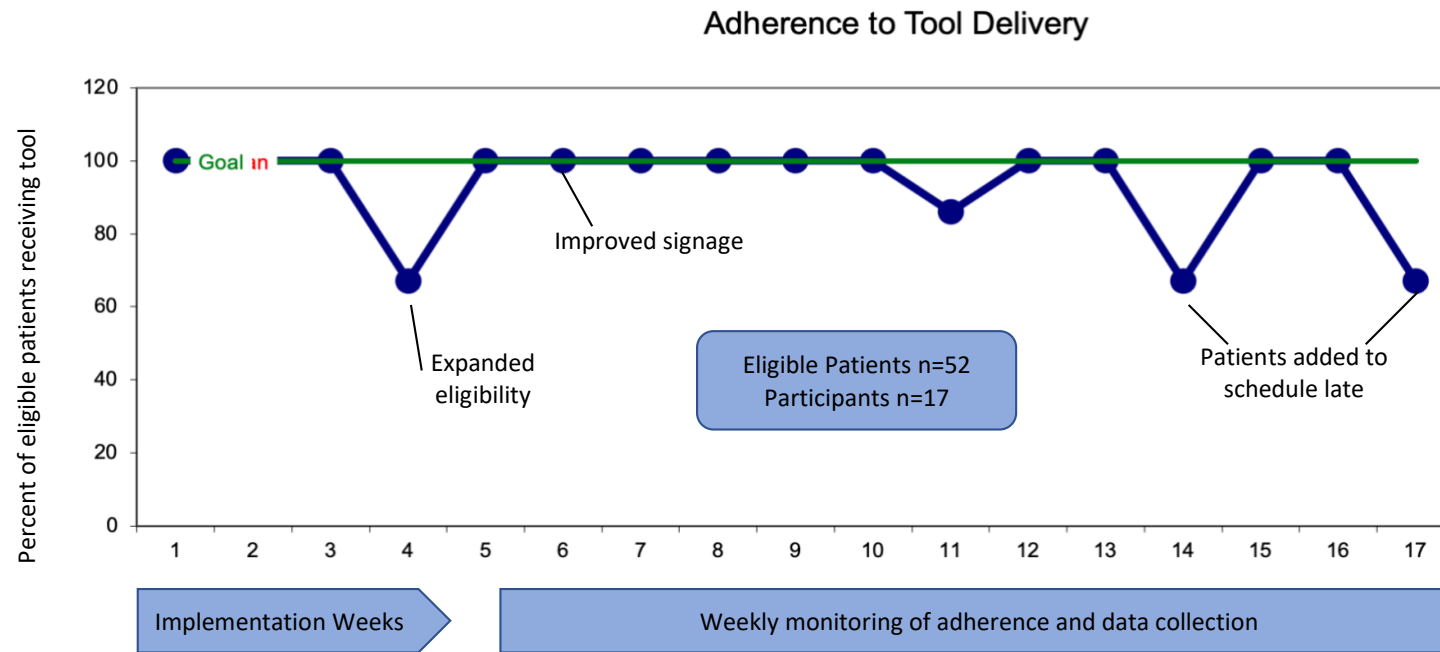
**Figure 3**

*Map of Process Change*



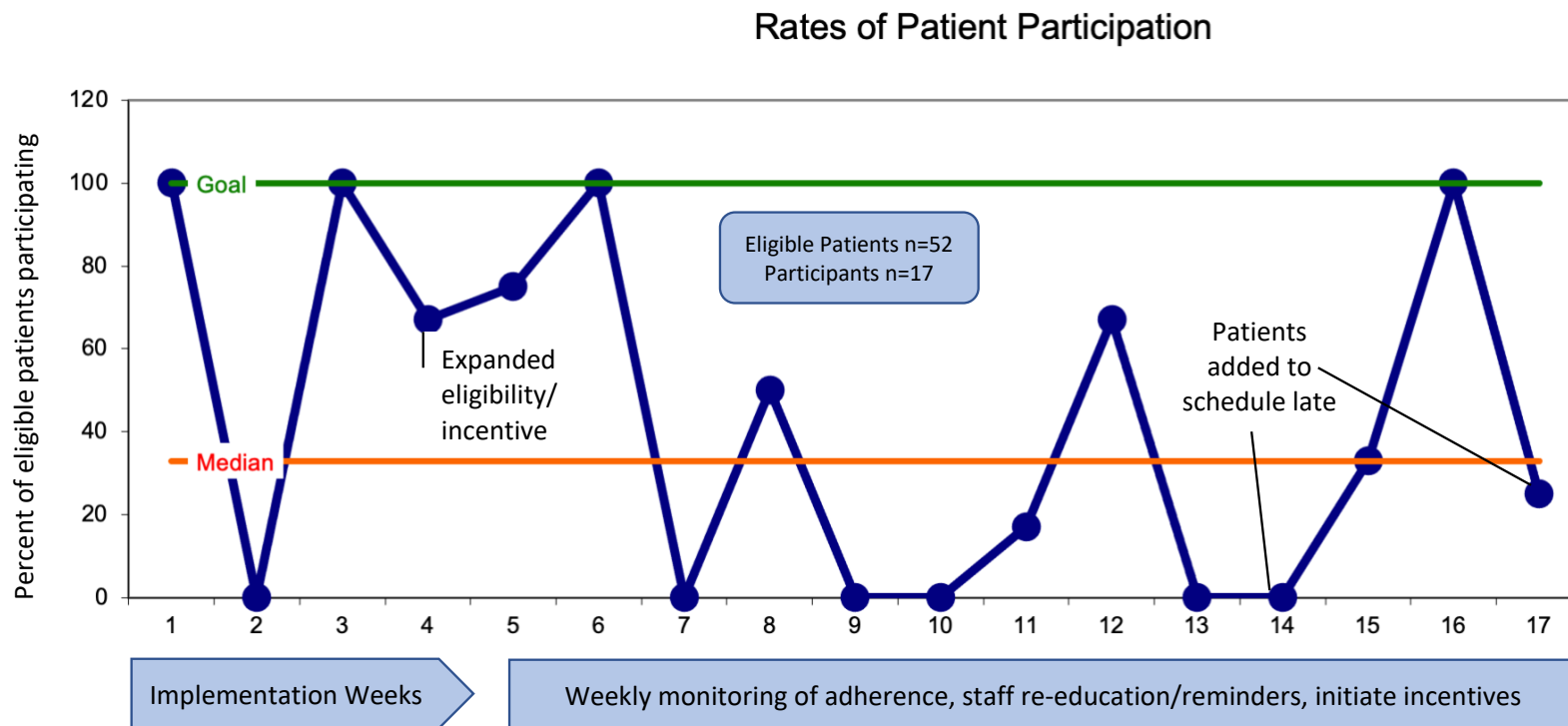
**Figure 4**

*Run Chart of Adherence to Process Change*



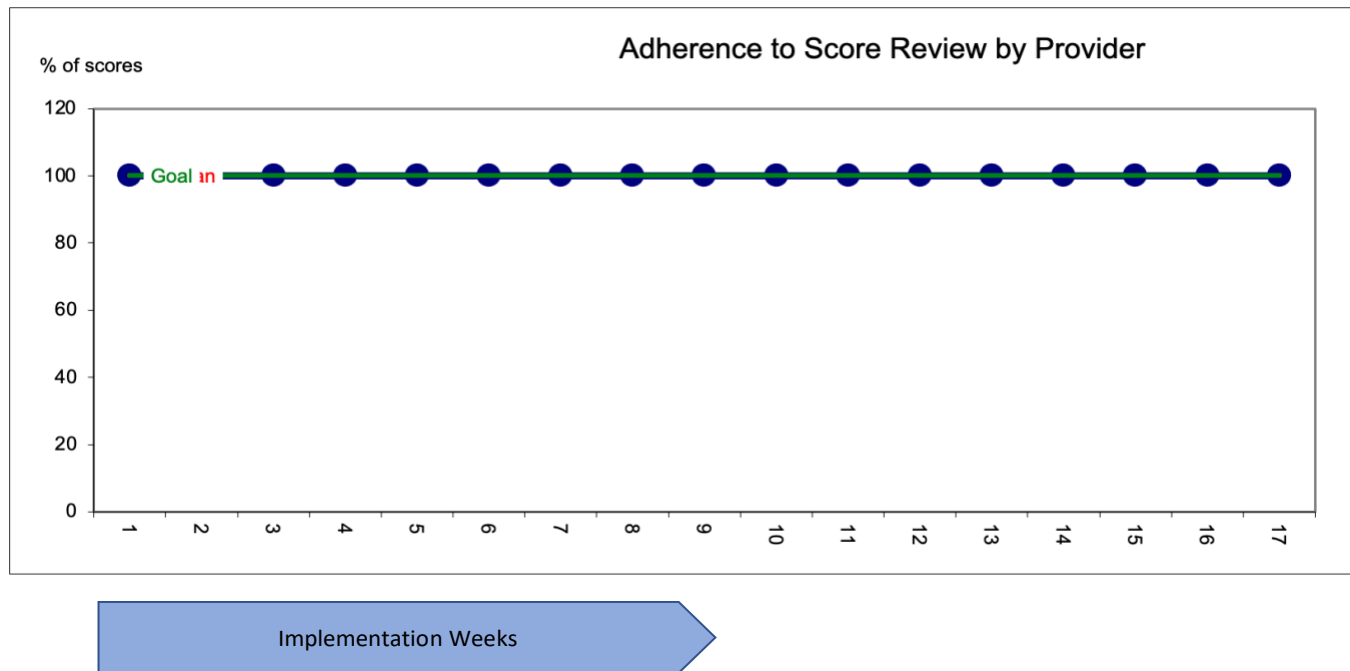
**Figure 5**

*Run Chart of Patient Participation by Implementation Week*



**Figure 6**

*Run Chart of Score Review by Provider by Implementation Week*



Appendix A

Transition Readiness Assessment Questionnaire

Transition Readiness Assessment Questionnaire (TRAQ)

Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_/\_\_\_/\_\_\_ Today's Date \_\_\_/\_\_\_/\_\_\_ (MRN# \_\_\_\_\_)

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

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

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
<b>Managing Medications</b>					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you reorder medications before they run out?					
4. Do you explain any medications (name and dose) you are taking to healthcare providers?					
5. Do you speak with the pharmacist about <u>drug interactions</u> or other concerns related to your medications?					
<b>Appointment Keeping</b>					
6. Do you call the doctor's office to make an appointment?					
7. Do you follow-up on referrals for tests or check-ups or labs?					
8. Do you arrange for your ride to medical appointments?					
9. Do you call the doctor about unusual changes in your health (for example: allergic reactions)?					
<b>Tracking Health Issues</b>					
10. Do you fill out the medical history form, including a list of your allergies?					
11. Do you keep a calendar or list of medical and other appointments?					
12. Do you tell the doctor or nurse what you are feeling?					
13. Do you contact the doctor when you have a health concern?					
14. Do you make or help make medical decisions pertaining to your health?					
15. Do you attend your medical appointment or part of your appointment by yourself?					
<b>Talking with Providers</b>					
16. Do you ask questions of your nurse or doctor about your health or health care?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
18. Do you ask your doctor or nurse to explain things more clearly if you do not understand their instructions to you?					
19. Do you tell the doctor or nurse whether you followed their advice or recommendations?					
20. Do you explain your health history to your healthcare providers (including past surgeries, allergies, and medications)?					
<b>Please circle how you feel about the following statements</b>					
	Not at all important	Not too important	Somewhat important	Important	Very Important
How important is it to you to manage your own health care?	1	2	3	4	5
How confident do you feel about your ability to manage your own health care?	1	2	3	4	5

## Appendix B

### Introductory Letter and QR Code

Dear Pediatric Cardiology Patient,

As a teenager who sees a heart specialist, staying healthy as you become an adult is important. This includes knowing your medical history and taking care of your health. Our team can help teach you this.

Please scan the QR code and complete the questionnaire on your phone. Filling it out is your choice and only your team will see your answers. After filling it out one of our nurse practitioners, [REDACTED] will call to set up a telehealth appointment. This appointment will focus on managing your condition.

If you have questions, you can talk to your doctor or call the Pediatric Cardiology Nurse Practitioners at [REDACTED]

Thank you for partnering with us in your care,  
The [REDACTED] Heart Program



*Note:* Was printed and handed out on official letterhead.