# Transition Program Redesign for Cardiac Congenital Patients

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**Abstract**

Congenital heart patients experience physical, mental, social, and financial stressors throughout their lifetime. Evidence-based practice supports congenital heart patients participating in a transition program to increase their heart health competency and independence as they grow into adulthood. Historically, most established transition programs are managed by pediatric cardiology under the directorship of the children's hospital; however, one transition program was failing under this model. Process improvement was completed and a novel approach where the Adult Congenital Heart Disease (ACHD) program managed the transition program was created. Next, a quality initiative project compared the rates of documentation compliance before and after the process update for assessment and education topics. The results showed a significant increase in documentation compliance of both the assessment and education topics. These results showed that a transition program for congenital heart patients can be successful when managed by the adult congenital program. Limited research is available on the workflow models of congenital heart transition programs; therefore, the introduction of a novel approach is significant.

*Keywords*: transition program, congenital heart, adult congenital heart disease, transition program model, transition assessment

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## Section I: Introduction

### Background

The wide spectrum of congenital heart diagnoses presents patients with neurocognitive issues, mental health concerns, and cardiac care needs. Transition programs have been shown to improve cardiac outcomes, lower health anxiety, and prevent gaps in care for this high-risk patient population (John et al., 2022). In this case, the term transition is referring to a transition to adulthood. The purpose of the transition program is to educate patients from the age of 12-18 on their congenital heart knowledge and assess their readiness to self-manage their heart health of patients from the age of 12-18. Typically, the provider or nurse will cover the patient's congenital heart anatomy, cardiac surgical history, age-specific concerns, transition-readiness assessments, and mental health well-being during a transition visit. Identified knowledge gaps ~~and information~~ gathered from the transition program is utilized by their cardiologist and nursing staff to prepare them to independently manage their heart health as an adult. Research has proven that patients who complete a transition program feel capable of managing their heart health independently; ~~therefore~~, have lower rates of Emergency Department (ED) visits, lower rates of health-related anxiety, and lower rates of negative cardiac outcomes (John et al., 2022).

### Organizational Needs Statement

Successful transition programs must include assessments of the patient's congenital heart knowledge and their readiness to manage their heart health as an adult (Leslie et al., 2020). At the targeted organization, the process for referrals, patient participation, and patient education in an established transition program was not functioning well for the medical staff. In addition, due to the unproductive process, evidence-based assessments and education were not documented.

The first problem identified was an ineffective process for completing transition program assessments. Unfortunately, due to staffing limitations, the pediatric clinic staff were unable to complete the necessary education and assessments for transition program patients. With this process, the compliance rate for transition program documentation was staggeringly low, at less than 5%. Pediatric Cardiology clinic staff reported there was insufficient time within a clinic slot to complete the transition program requirements. Established transition programs around the country demonstrate pediatric cardiology clinic staff completing the education and transition readiness assessments for patients; however, this model was unsuccessful.

After the completion of process improvement, the second problem identified was the ineffective process for entering and tracking transition program referrals. Due to the limited order options available in the electronic medical record (EHR) program, Epic, the staff had difficulty tracking transition referral data. There was no determinative feature in the referral order to establish if the purpose of the referral was for one of the following options: the patient needs transition education and assessment, the patient needs transition education and assessment along with the transition to the adult congenital program, or the patient is over the age of 25 and needs transfer to the adult congenital program. With the current order options, quality metric tracking of each referral type must be completed manually.

Manually abstracted data results support the ineffectiveness of the current process and transition referral metrics. During a period of 18 months, between July 2021 and October 2022, retrospective data showed a less than 5% completion rate of transition assessment documentation and a 0% completion rate of transition education documentation. Furthermore, 25% of the transition referrals sent to the Adult Congenital Heart Disease (ACHD) clinic, during the same 18-month period, were younger than 21 years old. Due to their young age, it is likely that this

group of patients has not had any transition program education or assessment completed. In an effort to increase awareness about the transition program, several ACHD staff members presented at a pediatric cardiologist staff meeting. Following this presentation and meaningful discussion about the benefits of a transition program with pediatric cardiologists, the number of referrals increased significantly. This increased the necessity to resolve the aforementioned problems.

Clinical guidelines on the care of congenital heart patients provided by the American Heart Association (AHA) and the American College of Cardiology (ACC) state that there is more than sufficient evidence to show the benefits provided to patients who go through a transition program, however, no standards or metrics are stated (Stout et al., 2018). In addition, an accrediting body the Adult Congenital Heart Association (2021) requires any accredited program to establish a transition program. However, no metric requirements are included in this accreditation standard. Although there are no quantitative benchmarks set by these organizations, program-specific goals for transition program metrics will provide target attainment measurements in this project. With the current process for this transition program very few accreditation standards, clinical-based guidelines, evidence-based practices, or quality metric goals were being met.

Health equity and safety of care are two mandatory components in healthcare development and healthcare policy. Every single patient deserves to be treated with standardized methods and with the same excellent quality of care. Equity, social justice, the safety of care, and cultural sensitivity are all factors that led to the development of the Triple Aim, then subsequently the Quadruple Aim, by the Institute for Healthcare Improvement (IHI). Like the

Quadruple Aim, the goals of this project are set to improve patient outcomes, improve the patient experience, lower costs, and improve the clinician experience (Bachynsky, 2020).

Transition program education and assessment are evidence-based practices that improve a patient's cardiac outcomes and lower their medical costs by decreasing the rates of complications and emergency department visits for cardiac-related symptoms (John et al., 2022). With lower rates of medical complications (John et al., 2022) and lower rates of anxiety and depression (Leslie et al., 2020) transition education and assessments will undoubtedly improve the patient experience. Lastly, this project was based on feedback from medical professionals voicing their concerns that there is insufficient time during a congenital cardiology outpatient visit to complete the required transition documentation. Updating the transition program process removes the stress put on the pediatric cardiology provider or nurse to complete additional assessments and education with the patient. This will in turn lessen the burnout that staff have experienced during outpatient congenital cardiology appointments (Bachynsky, 2020).

**Problem Statement**

The original process for this congenital heart transition program was inoperative due to staffing limitations, and the method of referral input. Due to the ineffectiveness of the original process, the completion rate for the necessary transition program documentation was less than 5%. This dysfunctional transition program model was likely to negatively affect patient satisfaction rates, the risk for anxiety and depression, and the risk for cardiac complications, the risk of ED visits, and the potential cost to the patient (John et al., 2022).

**Purpose Statement**

The purpose of this project was to examine the effectiveness of a transition program model that relies on the ACHD staff completing all the necessary requirements. A two-pronged

strategy, which included the implementation of a process improvement project and a quality initiative project, was utilized. Quality metrics, such as the completion rate of transition readiness assessments, the completion rate of transition education, and the number of referrals submitted for the transition program were measured before and after implementing this novel approach in a congenital heart transition program.

## Section II. Evidence

### Literature Review

Research focused on adult congenital heart patients is only from recent decades and is miniscule in size compared to the centuries of research focused on either pediatric cardiology or general cardiology. Therefore, research focused on congenital heart transition programs is also narrowed into a specific niche of literature. Warnes et al. (2008) was one of the first guidelines published on the management of adult congenital heart patients in the United States and was supported by the participation of the ACC and AHA. Within these original guidelines, the authors and task force participants included support stating the importance of creating a transition program for adolescent congenital heart patients (Warnes et al., 2008). Following Warnes et al. (2008), Baumgartner et al. (2010) in partnership with the European Society of Cardiology (ESC) also endorsed each adult congenital program creating a transition program for adolescent congenital heart patients. Updated guidelines or scientific statements from cardiology-research associations have consistently included the same recommendation, but with each year the body of evidence to support these transition programs grows stronger and larger (John et al., 2022). Although the limited number of research articles could be viewed as a disadvantage, each article that is published holds more meaning to this specialized population of patients and the healthcare staff that work with them. It would be difficult to find an example within the literature that does not offer data to support the benefits of a congenital heart transition program. Weaknesses within the current literature include low quantities of experimental research design studies and research focusing on congenital heart transition programs in low-income or low socio-economic background populations (Moons et al, 2021).

#### *Current State of Knowledge for Population*

Congenital heart defects are the most common birth defects and currently, over two million Americans are living with congenital heart disease (CHD). Prior to surgical advances and medical treatments, the mortality and morbidity rates were alarmingly high for moderate to severe defects. In fact, some complex cardiac-structural findings are never survived past the first month of life unless surgery is completed. Due to current surgical and medical advancements over 90% of newborns with CHD can survive into adulthood (Kovacs et al., 2022). The adult congenital heart disease (ACHD) population is a new population of patients that have never existed before, especially with severely complex congenital diagnoses. After decades of increasing surgical options for these patients, for the first time, adult congenital heart patients now outnumber pediatric congenital heart patients (Kovacs et al., 2022). This created a need for the care management of adolescent, adult, and advanced-age congenital heart patients.

***Evidence to Support the Intervention***

There is a great amount of variation in the severity of congenital heart defects and surgical experience in congenital heart patients. Some patients never require surgery or an intervention procedure, while others have survived multiple open-heart surgeries throughout their lifetime. Due to the differing levels of physical burdens and medical treatment requirements, adult congenital patients have an assortment of psychological, social, and psycho-social stressors (Roseman et al., 2021). These challenges face congenital heart patients from childhood into adulthood. To promote health independence in conjunction with a decrease in parental involvement as patients get older, transition programs should assess the transition readiness of patients and educate the patient on what is important to know about their heart (Leslie et al., 2020).

In addition, depending on the diagnosis, each congenital heart patient requires differing levels of disease-related knowledge, diagnostic testing, and congenital cardiology care. Transition programs are crucial in raising awareness regarding the need for lifelong cardiology care with adolescent congenital heart patients (Stout et al., 2018). Lack of knowledge and understanding about their congenital cardiology history increases the risk of a gap in care during adolescent ages (Leslie et al., 2020). A gap in care for these patients may result in serious health outcomes. Disease sequela can lead to the development of heart failure, pulmonary hypertension, arrhythmias, or other complications that require intervention or surgery (Kovacs et al., 2022).

Transition-focused research confirms that patient participation can lead to an increase in health independence and a decrease in negative outcomes, but results have also shown a reduction in anxiety and depression. For example, Huntley et al. (2019), and Leslie et al. (2020), both observed that a patient's health competence and mindset will affect an adult congenital heart patient's likelihood of experiencing anxiety and depression. Huntley et al. (2019), found in their study participants that patients who experienced denial about their cardiac health or those who described a negative expectation of their cardiovascular healthcare team were linked to higher depression symptoms and mood disorders. Similarly, Leslie et al. (2020), studied participants who did not know their congenital heart history and expressed low levels of perceived health competency were associated with increased levels of anxiety and depression.

The first clinical practice guidelines on the management of congenital heart patients were published in 2008 by the ACC and the AHA (Warnes et al., 2008). Within the evidence review the authors stated that the suggested practice guidelines and recommendations are evidence-based, when possible. Due to the limited amount of literature and peer-reviewed research on adult congenital patients available in 2008, the AHA and ACC did not have comparable amounts

of evidence when Warnes et al., (2008) published the initial guidelines. Within the original ACC/AHA guidelines, it was recommended that a formal transition program be established to guide patients into adulthood (Warnes et al., 2008). The most recent ACC/AHA guidelines for the management of congenital heart patients include a strong recommendation for creating an established transition program to avoid gaps in care and increase congenital diagnosis knowledge for adolescent patients transitioning into adulthood (Stout et al., 2018). Up-to-date clinical practice guidelines (Stout et al., 2018) and an accrediting body, the Adult Congenital Heart Association (2021), both endorse having a transition program; however, no framework or program requirements are listed.

Several examples of transition program models have been introduced in published research. Some of these models include nurse-led clinic-based education, multidisciplinary transition clinic, comprehensive transition program, electronic health tools, joint clinic model, and transition-coordinator model (John et al., 2022). De Hosson et al. (2024) concluded that a nurse-led congenital heart transition program, including pediatric cardiology and adult congenital staff, provides beneficial effects to the well-being and cardiac knowledge of its patients. De Hosson et al. (2024) also supported the use of individualized transition education topics based on the patient's diagnosis complexity and knowledge gaps. Gaps in knowledge and self-management abilities are identified using transition assessments (John et al., 2022).

In addition to deciding which transition program model to utilize, the program must also determine what transition assessment tools to use. Evidence-based transition tools to measure transition readiness, disease-specific knowledge, health anxiety, self-management skills, and health literacy are recommended assessments that should be utilized within congenital heart transition programs (John et al., 2022).

Current literature and clinical practice guidelines support the participation of congenital heart patients in a transition program with positive effects on the patient regardless of their diagnosis or diagnosis severity. Based on current research, established programs that provide the most efficient transition to adulthood should include the following: completion of an assessment of transition readiness, an assessment of congenital diagnosis knowledge, promotion of lifelong cardiology care, and education on age-specific cardiac care (Kovacs et al., 2022).

**Evidence-based Practice Framework**

The use of evidence-based practice (EBP) in a clinical setting is necessary to obtain positive outcomes. Nurses are able to analyze scientific evidence and come up with application solutions for patient-centered problems. When creating and organizing this project it was essential to choose the best possible EBP framework to apply to the identified problem. One of the most validated and published models, The Iowa Model, has been revised to ensure the translation and implementation of research principles. Over 20 years ago, Titler et al. (1994) introduced a model aimed at solving problems for clinical leaders. The Iowa Model was developed as a process framework so that research data could be translated into clinical practice, with improved outcomes as a result (Titler et al., 1994). Since its revision in 2017, The Iowa Model Revised is an established EBP framework that has been utilized by clinicians to answer questions and find useful solutions (Hanrahan et al., 2019). Both The Iowa Model (Titler et al., 1994) and The Iowa Model Revised (Hanrahan et al., 2019) are multi-step processes that are more complex when compared to other validated EBP frameworks. Similarly, this process improvement and quality initiative could be described as complex; therefore, it was determined that it would benefit the flow of this project to utilize The Revised Iowa Model as the EBP framework.

The Revised Iowa Model is a thorough procedure, using triggers, evidence appraisal, evidence integration, outcome monitoring, and findings dissemination (Hanrahan et al., 2019). The goal of this project was to follow the set steps within the Revised Iowa Model so that successful implementation of EBP would lead to positive data findings and sustainable organization processes. This project began with the identification of a problem, or a trigger, as described in the Revised Iowa Model. The next step was process improvement where the current evidence was used to develop an updated process and integration plan. Next, the results of the process implementation were gathered as quality metrics to provide evidence of the efficacy, or outcome monitoring as described in the Revised Iowa Model (Hanrahan et al., 2019).

**Ethical Consideration & Protection of Human Subjects**

The Collaborative Institutional Training Initiative (CITI) Program was completed by the project manager as an educational program focused on the importance of protecting human subjects in research. Completion of CITI training is necessary for research organizers to avoid conflicts of interest and to conduct best practices in clinical research. Modules covered in the CITI training help the researcher avoid violations of bioethics or putting participants at risk (CITI, 2022).

The targeted site requires all research projects to be described in detail and submitted for review by their Institutional Review Board (IRB). A complete IRB application was submitted to the target site IRB by the project manager. The IRB review provided contingencies and suggested updates to ensure that no risk to the patient or their health information would occur as a result of their participation in the project. The risk to the patient for any physical harm, mental harm, or risk of health information exposure is extremely low in this project. Participation in transition programs is evidence-based (Stout et al., 2018), and educating congenital heart patients

on the transition program at the targeted site has been a suggested process for years. The IRB application was first submitted on September 8th, 2023. Stipulations were returned by the IRB to the PM on September 27th, 2023. The PM returned the IRB application with clarifications and changes made based on the provided stipulations on October 24th, 2023. On October 24th, 2023, the project site IRB responded that a determination was made. This determination stated that the project does not require IRB approval and a notice of study approval by the IRB with a data security level of III.

In addition, the health information of these patients was previously shared with ACHD staff to ensure collaboration and best clinical practice, so no additional staff were exposed due to data tracking for the project. Only staff with approved access to quality data servers were allowed to view transition program data and patient information.

## Section III. Project Design

### Project Site and Population

The project was completed at a state-funded public hospital with an established pediatric cardiology program and an accredited adult congenital heart program. The population in this project included both clinic staff and providers who worked at the project site location. Providers and clinic staff within the population were working at either a pediatric cardiology or an adult congenital outpatient clinic setting located at the project site. In addition to the outpatient clinic setting, some of the project population were working on a telemedicine platform available at the site's outpatient clinic setting, following the process improvement phase.

#### *Description of the Setting*

There were several different settings used during the completion of this project. Initially, the transition program was completed by pediatric cardiology staff within the outpatient pediatric cardiology clinic locations. Within the project site system, there were four different clinic locations for the pediatric cardiology clinic. No telemedicine visits were completed at any of the pediatric cardiology clinic settings. Following the process improvement, the setting changed to one of two different adult congenital heart outpatient clinic locations or the project site telemedicine platform.

#### *Description of the Population*

The population prior to the process improvement included only pediatric cardiology clinic staff and providers who worked at the site location. Providers were either a Doctor of Osteopathic Medicine (DO), Medical Doctor (MD), Physician's Assistant (PA), or Nurse Practitioner (NP). Clinic staff at the pediatric cardiology consisted of either a Certified Medical Assistant (CMA), Licensed Practical Nurse (LPN), or Registered Nurse (RN).

Following the process improvement, the population included a registered nurse or a provider at the adult congenital clinic location. However, it was either an adult congenital NP or an adult congenital nurse who worked at the site location's outpatient clinic or telemedicine platform.

**Project Team**

The project team included the project manager (PM) and a DNP-prepared site champion faculty member. During process improvement, the PM's role was to document staff feedback, take notes of suggestions, update program policies, and then organize the process updates into diagrams and process flow maps for staff to use. During quality improvement, the PM was responsible for tracking and recording referral numbers and referral data to adult congenital for the purpose of a transition visit as well as staff documentation compliance. Transition-readiness assessments documented during the quality initiative were the responsibility of either the PM or the adult congenital nurse practitioner. The site champion faculty member, or DNP-prepared adult congenital nurse practitioner, was responsible for completing transition-focused education and documenting this in the office visit note.

**Project Goals and Outcome Measures**

The project goals were to improve patient participation in the transition program and to improve staff documentation compliance with transition program charting. In order to meet these goals, it was necessary to make changes to the original process flow. The first segment of the project included a process improvement. Following the project sites' annual adult congenital heart quality data meeting, a root cause analysis was completed to determine the areas of improvement and possible solutions to the low staff compliance with required transition documentation. Next, the identified action strategies were reflected in updated policies, updated process flow maps, and updated patient education diagrams. Once, the process improvement was

completed, the quality initiative segment of the project began. Quality measures were tracked, documented, and organized as results, then finally reviewed during the quality initiative. Quality measure data was gathered via quality reports, secondary data collection, and chart abstraction by the PM. To confirm the efficacy of the updated process flow, quality measure results were compared to the data results gathered prior to the process improvement. Data organization and analysis were completed using Excel and stored in a secured site location quality drive.

**Description of the Methods and Measurement**

The first quality measure collected was the number of patients who participated in the transition program. Prior to the process improvement, chart abstraction, and secondary data collection methods were used by the PM to track staff documentation of transition-readiness assessments and transition-focused education. Staff charting of these transition documents was counted as participation. Chart abstraction was the only method to track staff documentation and project site data showed a staff documentation compliance rate of less than 5%, during an eight-month time period spanning from 2022-2023.

After process improvement was completed, an additional data measure to show patient participation was tracked using referral orders. The updated process map shifted the responsibility of transition documentation from pediatric cardiology to adult congenital cardiology. A referral order to adult congenital cardiology, with the note “transition visit” was decided to be the method of communication between pediatric cardiology and adult congenital. This referral order signals to adult congenital that the pediatric cardiology provider would like the patient to participate in the transition program. For each patient for whom a transition visit referral was ordered, staff documentation compliance was tracked. A goal to increase

documentation compliance by 15%, to meet a goal of 20% documentation compliance was decided by the P.M.

Staff documentation compliance of a transition-readiness assessment is another quality measure tracked and measured in this project. The transition-readiness assessment would be documented by the adult congenital nurse or the adult congenital nurse practitioner, according to the process updates.

Staff documentation compliance of transition-focused education is another quality measure tracked and measured in this project. The transition-focused education would be documented by the adult congenital nurse or the adult congenital nurse practitioner, according to the process updates. Transition education topics for ages 12-15 differ slightly from the education topics suggested for ages 16-18+. Certain transition education topics, especially those for ages 16-18+ are complex and would be best reviewed and documented by the nurse practitioner. Due to the large spectrum of congenital diagnosis complexity and varying self-management needs of the patients, these education topics were individualized for each patient.

For each quality measure collected during the quality initiative, a goal to increase each by a minimum of 15% was determined by the PM. Unfortunately, AHA and ACC guidelines do not provide goals or minimum data rates for recommendations on transition programs (Stout et al., 2018). A goal to increase documentation compliance by 15%, to meet a goal of 20% documentation compliance was decided by the P.M.

***Discussion of the Data Collection Process***

Data for the project was collected using quality department reports from the site location, secondary data collection, and chart abstraction. The PM was responsible for tracking, collecting, and storing data. After process improvement was completed and the process flow map

was updated, referral orders were used as a data source. Once a referral was sent from pediatric cardiology to adult congenital for a transition visit, the chart could be reviewed for documentation compliance, once the visit was completed

**Implementation Plan**

The first phase of the project began with the review of staff documentation compliance with the project site transition program in the summer of 2023 and a decision to complete a root cause analysis swiftly followed. After this root cause analysis was completed, a completely new process flow was created for the congenital heart transition program. Staffing or clinic time slots were unable to be changed in the pediatric cardiology clinic to accommodate the additional time needed to complete the transition documentation. This led to the new implementation plan whereby the adult congenital staff would be responsible for completing all transition documentation and transition education. This implementation plan could be designated as nurse-led since the adult congenital staff completing these include a nurse or nurse practitioner. This novel approach meant that established congenital heart clinic patients ages 12 and above must be referred to the adult congenital program, only for the reason of transition documentation. The referral order was entered by the pediatric cardiology staff to adult congenital cardiology with a comment of “transition”. The referral served as the notification to the adult congenital program that the pediatric cardiologist decided that the patient needed transition assessment and transition education. Staff from both pediatric cardiology and adult congenital cardiology were responsible for explaining the reason for the referral and transition. Since the transition assessment and transition documentation were not being completed by their pediatric cardiologist or pediatric cardiology staff at an outpatient clinic setting, the referred patient would be scheduled to see the adult congenital nurse practitioner either at a clinic location or via the telemedicine platform.

These appointments were designated as transition visits. By the fall of 2023, project site policies, processes, process flow diagrams, and patient education information were all updated to reflect the new congenital heart transition program process.

After completion of the process improvement, the new implementation plan was followed starting in the winter of 2023 into the spring of 2024. During this next phase of the quality initiative, the data and quality measures were tracked and saved for review. Once the quality initiative phase was completed in the summer of 2024, the results were reviewed. Finally, the efficacy of the updated process could be determined.

## Section IV. Results and Findings

### Results

During the set time-period of January to May of 2024, the Pediatric Cardiologists submitted 31 referrals to adult congenital, to complete a transition visit. The ages ranged from 16 to 46. Of those 52% (n=16) of the referrals were designated females, and 48% (n=15) were designated males. One of the designated female patients did identify as a male, and their electronic health record reflected this change.

The most up-to-date guidelines from the AHA and ACC provided a new classification system for the level of congenital heart lesion complexity (Stout et al., 2018). These classifications consider the anatomy complexity as well as the physiological complexity. Physiological complexity looks at the patient's functional abilities, presence of valve disease, pulmonary hypertension, diagnosis of cardiac arrhythmias, aortic dilation, and level of cyanosis (Stout et al, 2018). Of the referrals, 29% (n=9) had an assigned complexity level of simple, 29% (n=9) of the referrals had an assigned complexity level of moderate, and 42% (n=13) of the referrals had an assigned complexity level of severe.

Also, 3% (n=1) of the referrals were of Hispanic race, 19% (n=6) of the referrals were of African-American race, and 78% (n=24) of the referrals were of Caucasian race. Lastly, 90% (n=28) of the referrals were from out of county, and 10% (n=3) of the referrals lived within the same county as the project site.

Out of the 31 referrals, 32% (n=10) scheduled a transition appointment. These patients scheduled and attended the transition appointment either virtually or in the clinic. Out of these completed transition visits, 64% (n=8) were completed virtually and 26% (n=2) were completed

in the clinic. One patient scheduled a transition appointment but then canceled and the staff was unable to reschedule the appointment.

**Discussion of Major Findings**

The documentation compliance of staff for transition assessments, for patients that completed a transition appointment, was 80% (n=8) compliance. Based on the determined outcome goals, this exceeds the goal of increasing the documentation compliance rate from 5% to 20% or above. Barriers to documentation compliance of the transition assessment were when the transition appointment was scheduled through emails or my chart messages. The adult congenital staff documented multiple attempts to contact patients on the phone to complete a transition assessment before their appointment. Due to the number of questions on the transition assessment, these questions were only completed by staff either in person or on the phone. Two patients had a transition assessment completed at a prior appointment but then declined to schedule a transition appointment. These transition appointments were not included in the 80% assessment documentation compliance.

Documentation compliance of staff for transition education topics, for patients that completed a transition appointment, was 100% (n=10). These transition topics were determined based on the patient's age and results from the transition assessment. Please reference Appendix C to see the list of possible education topics documented by staff during a transition appointment. Based on the determined outcome goals, this exceeds the goal of increasing the documentation compliance rate from 5% to 20% or above. Please reference Appendix D for a diagram of these goal results.

Out of the total group of referrals received, 65% (n=20) did not complete a transition visit. The reasons why were that 50% (n=10) declined, 35% (n=7) were unable to contact, and

15% (n=3) were delayed due to cardiac health concerns. To categorize a patient as declined, the patient must have declined to schedule after the adult congenital staff explained the benefits of completing a transition appointment as well as a description of what would be covered in these appointments. Staff would always notify the patient that they have the choice of virtual or in-clinic appointments. One patient who declined was moving to another state and did not wish to complete the visit before moving. Significant efforts were made to reach the seven patients who were unable to be contacted, including staff making multiple phone calls to all listed numbers, sending emails, and sending mychart messages. Unfortunately, an overwhelming 86% (n=6) of the patients that were unable to be contacted, were classified as severe complexity with their congenital heart history.

Three patients, within this group, were delayed for a transition appointment after the adult congenital staff spoke to the patient and determined that there were concerning cardiac symptoms. Due to the risk of congenital heart disease sequelae, the adult congenital staff worked to coordinate diagnostic studies and evaluations in the clinic rather than scheduling a transition appointment. For all three of these patients, this meant delaying the transition appointment outside of the window of time for data capture.

## Section V. Interpretation and Implications

### Costs and Resource

Adult congenital staff and designated hours to commit to the transition program were required to complete the necessary work. The staff spent time processing the referrals to the transition program, scheduling the transition appointments, gathering patient records, and completing the transition appointments. Clinic resources were also needed, such as clinic rooms for patient appointments, clinic space with a desk and phone, and clinic telehealth rooms with technology capabilities for virtual appointments. Since all transition appointments were added to the adult congenital clinic, additional time slots were added to the clinic schedule to accommodate these patients.

Computer resources were necessary to request, download, and access patient records, including operative reports, cardiac catheterization diagnostic reports, and cardiac catheterization intervention reports. Additionally, computer resources were used to create patient handouts, infographics, education topic handouts, a patient-specific heart diagram with notes, and a patient-specific operative history report. Please reference Appendix E for a handout example.

### Implications for Patients

As a result of the process update, patients who were referred to the transition program must complete a separate appointment. This requires additional coordination by staff and an additional cost for the patient. There is an emotional implication for the patient and their family when they have to communicate with a new group of staff, especially when they may have seen the same pediatric cardiologist since birth. Lastly, to create an individualized operative history report the patient may need to sign record requests before the transition appointment.

### Implications for Nursing Practice

Implications for the nursing staff are likely the most substantial after the process improvement. Processing transition program referrals, scheduling patients, rescheduling patients, coordinating patient needs, managing record requests, and balancing clinic schedules with other adult congenital patients are all additional responsibilities of the adult congenital staff. Staff workloads before the process improvement were already substantial, but the adult congenital staff had to adapt in order to accommodate these additional demands from the transition program. For the adult congenital nurse practitioner, there was an increase in clinic appointments and before each transition appointment, the patient's records and transition assessment results must be reviewed.

**Impact for Healthcare System(s)**

To maintain patient participation in this updated transition program, there must be continued support from leadership, and continuous resources from the project healthcare system. Updates to the electronic medical record system to streamline the new process of entering a referral to the transition program is a responsibility of the healthcare system. Education for staff and stakeholders on the updated process may be necessary to maintain program support.

**Sustainability**

Maintained support of staffing needs and designated hours for the transition program is the minimum of what would sustain this process update. To sustain and expand this process improvement process within the transition program additional staffing, additional clinic resources, and additional staff time devoted to the transition program are all necessary.

**Dissemination Plan**

A presentation of quality initiative findings and evaluation of the process improvement is crucial to obtaining feedback from pediatric cardiology staff, leadership, and stakeholders. This

feedback will assist staff in creating plans for continued implementation and further updates to the process.

## Section VI. Conclusion

### Recommendations for Others

Comparison of adult congenital-owned transition programs to traditional pediatric cardiology-owned transition programs would be novel and insightful for other programs. There are no published examples of a transition program that is organized similarly to the process improvement created in this project. A benefit comparison for the patient between the two types of programs would be interesting and cutting-edge. Research on the importance of having patient-specific operative records before completing transition program education would provide helpful direction on the necessity of this part of the process.

### Recommendations Further Study

Future areas of focus include measuring patient satisfaction and measuring a decrease vs increase in the patient's heart-health knowledge, changes in health anxiety following transition program participation, and removing barriers to patient participation. Evaluation of the transition program assessment and education topics should be completed to identify the need for updates, if necessary. An assessment on the inclusion of the cardiology-behavioral-sciences therapist in the transition may be beneficial to reducing health anxiety and addressing self-esteem related to open heart surgery scars.

AHA/ACC guidelines recommend that transition programs focus on 12-18-year-olds to improve congenital heart knowledge and self-management skills prior to adulthood (Stout et al., 2018). The goal of this process improvement was to have the pediatric cardiologists refer patients within the 12-18 year-old range to complete a transition program appointment. However, an overwhelming majority of the referrals were of patients over the age of 18. Regardless of their

age, these patients have not participated in the transition program or received transition-focused education.

The majority of the referrals sent to the transition program were of young adult patients who needed a transition appointment prior to their next follow-up. In most cases, their pediatric cardiologist suggested that the patient complete the transition appointment before seeing adult congenital cardiology for the next follow-up appointment. It is possible that the newness of the adult congenital program at the project site created a backlog of young adult patients who needed to transfer their care from pediatric cardiology to adult congenital. The pediatric cardiologists preferred to refer patients to the transition program and then refer them for a transfer of care to ACHD as a way of subtly transitioning the patient out of pediatric cardiology. Participation for these patients arguably still has the same positive effects; however, this raises the question, should someone be responsible for identifying eligible transition program patients within the suggested 12-18 age-range to remind the pediatric cardiologists of putting the referral only for a transition visit? Is there a better option to capture patients within the suggested age range?

**Final Thoughts**

For the project site leadership and staff, they must determine if the process improvement benefited everyone or are further updates needed. Also, if staffing within the pediatric cardiology clinic improves, should the updated process continue, or should the pediatric cardiology staff take responsibility for the transition program? Leadership and stakeholders must determine if continued support and resources can be provided to the transition program, and what is the next step for the program.

Improvement in transition program participation, staff documentation compliance with transition assessments, and staff documentation compliance with transition education topics were

all successfully observed after the completion of the process improvement. The updated process is novel and lacks research support, but with the observed progress in project outcomes should this be a recommended program design.

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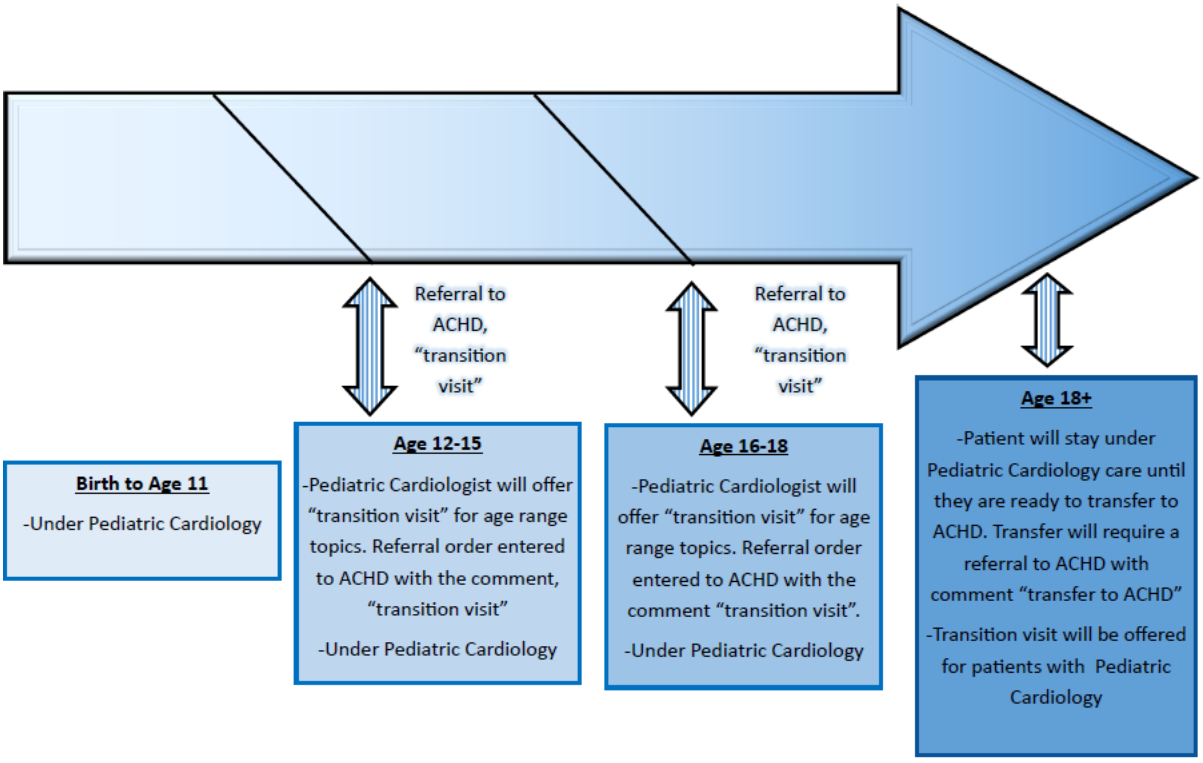
## Appendix A

Process Flow Map Following Process Improvement




*Note.* This figure shows the process flow map for the congenital heart program with updates, following the process improvement.

# Appendix B

IRB Response from Project Site

**From**: Office of Human Research Ethics

**Date**: 10/24/2023
**RE**: Determination that Research or Research-Like Activity does not require IRB Approval
**Study #:** 23-2252

**Study Title**: A Process Improvement and Quality Initiative Project by the Adult Congenital Heart Disease Transition Program

This submission, Reference ID 409034, was reviewed by the Office of Human Research Ethics, which has determined that this submission does not constitute human subjects research as defined under federal regulations [45 CFR 46.102 (e or l) and 21 CFR 56.102(c)(e)(l)] and does not require IRB approval.

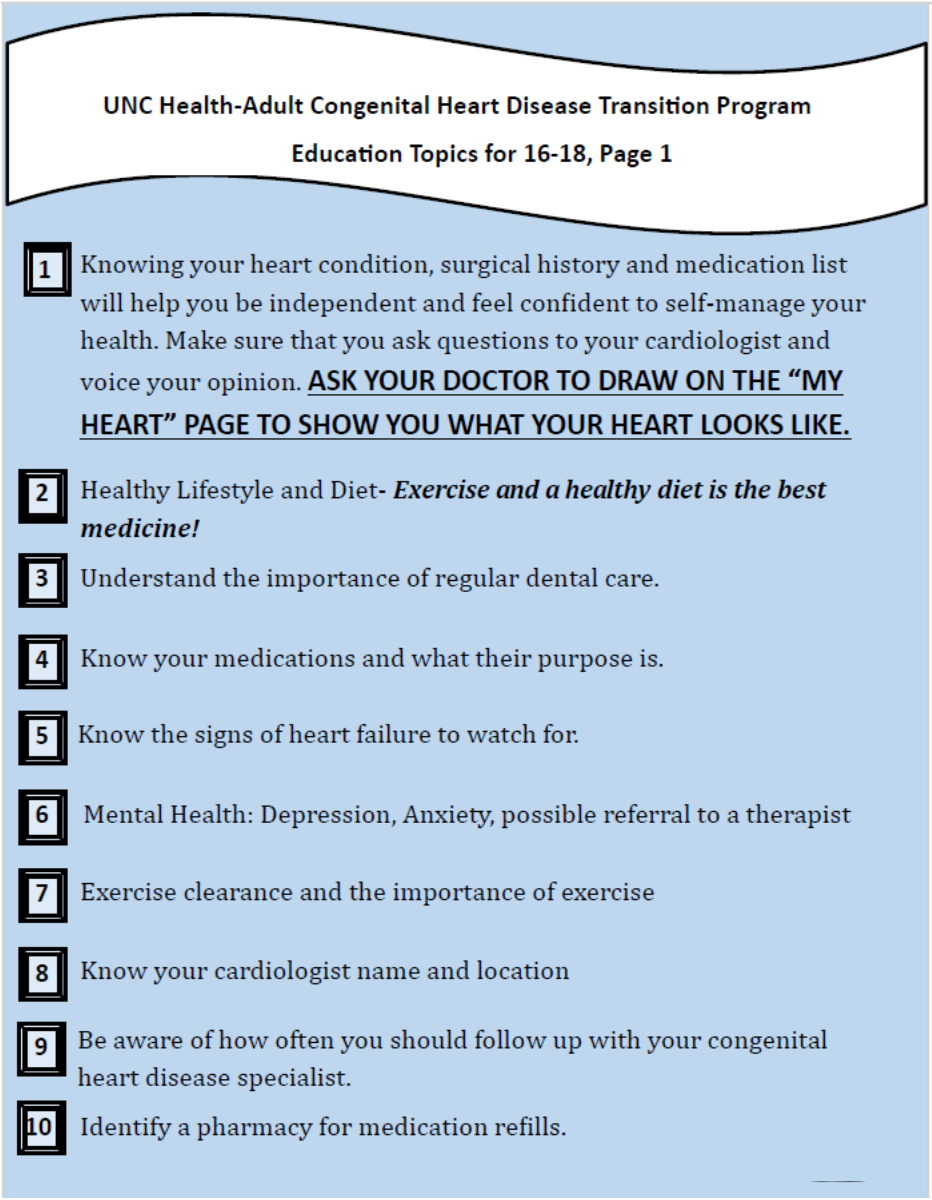
Date: 10/24/2023
RE: Notice of Study Approval by the IRB with the Data Security Level of Level III

Study #: 23-2252
Study Title: A Process Improvement and Quality Initiative Project by the Adult Congenital Heart Disease Transition Program
PI: Gobble, Emily

The Institutional Review Board has finalized its review of this study. Based on information the Investigator provided, this study meets the criteria for Level III data security requirements.

## Appendix C

Transition Education Topics from Patient Handouts



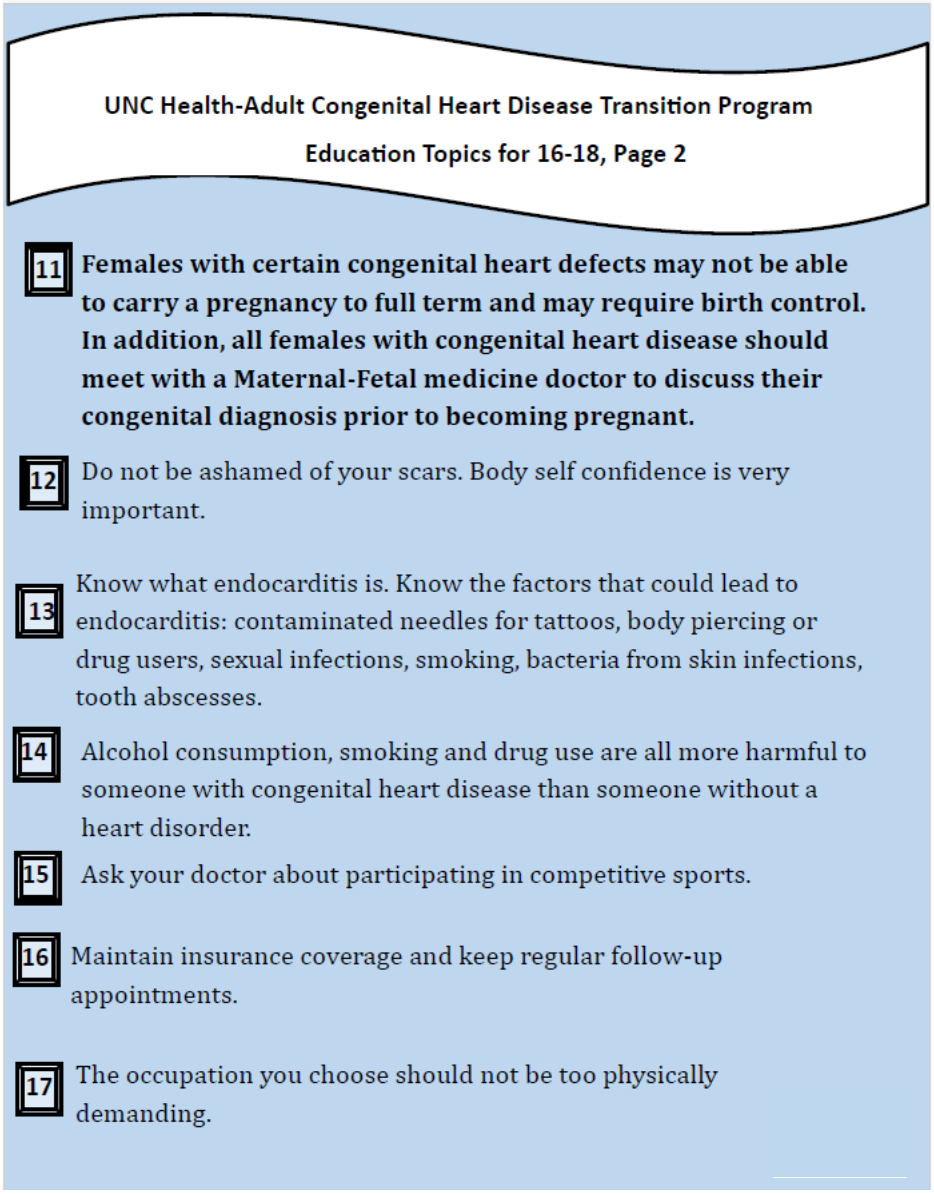
**UNC Health-Adult Congenital Heart Disease Transition Program**

**Education Topics for 16-18, Page 1**

1. Knowing your heart condition, surgical history and medication list will help you be independent and feel confident to self-manage your health. Make sure that you ask questions to your cardiologist and voice your opinion. **ASK YOUR DOCTOR TO DRAW ON THE "MY HEART" PAGE TO SHOW YOU WHAT YOUR HEART LOOKS LIKE.**
2. Healthy Lifestyle and Diet- ***Exercise and a healthy diet is the best medicine!***
3. Understand the importance of regular dental care.
4. Know your medications and what their purpose is.
5. Know the signs of heart failure to watch for.
6. Mental Health: Depression, Anxiety, possible referral to a therapist
7. Exercise clearance and the importance of exercise
8. Know your cardiologist name and location
9. Be aware of how often you should follow up with your congenital heart disease specialist.
10. Identify a pharmacy for medication refills.

*Note.* This is a patient handout for transition appointment education topics, focused on patients ages 16-18. These education topics are recommendations but do not include all education topics that may be covered during a transition appointment.

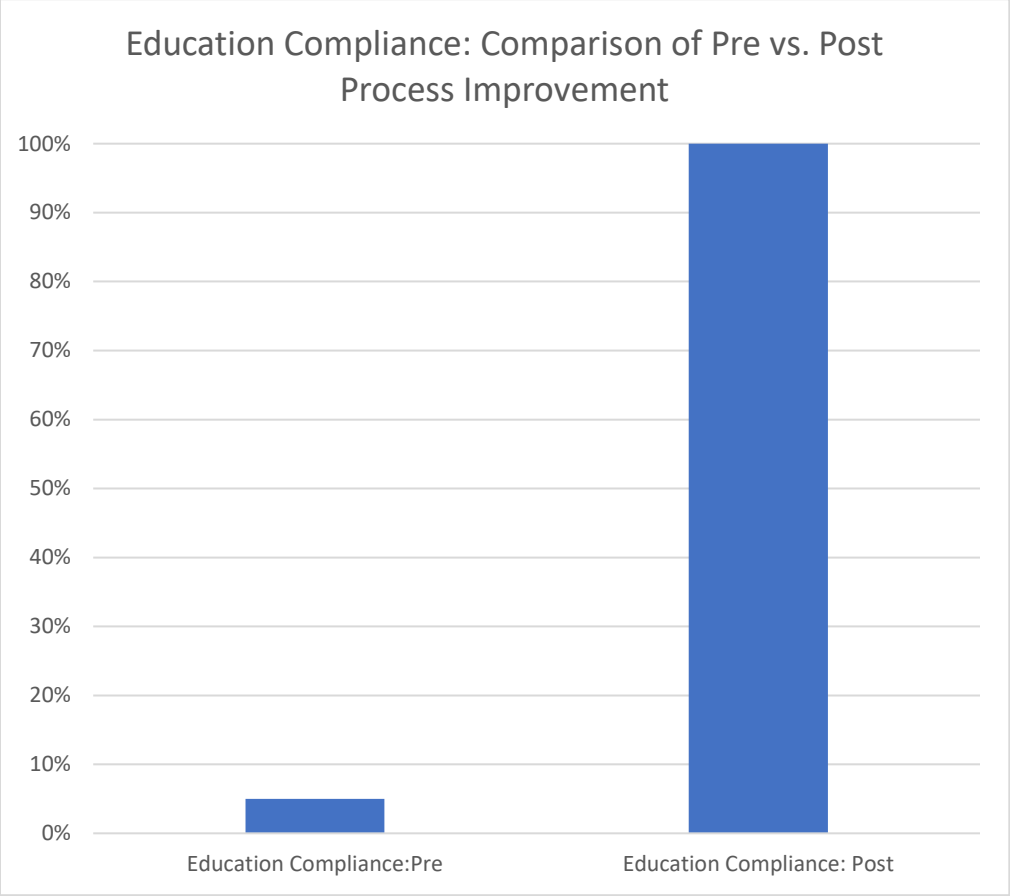
**Appendix C, continued**




*Note.* This is a patient handout for transition appointment education topics, focused on patients ages 16-18. These education topics are recommendations but do not include all education topics that may be covered during a transition appointment.

## Appendix D

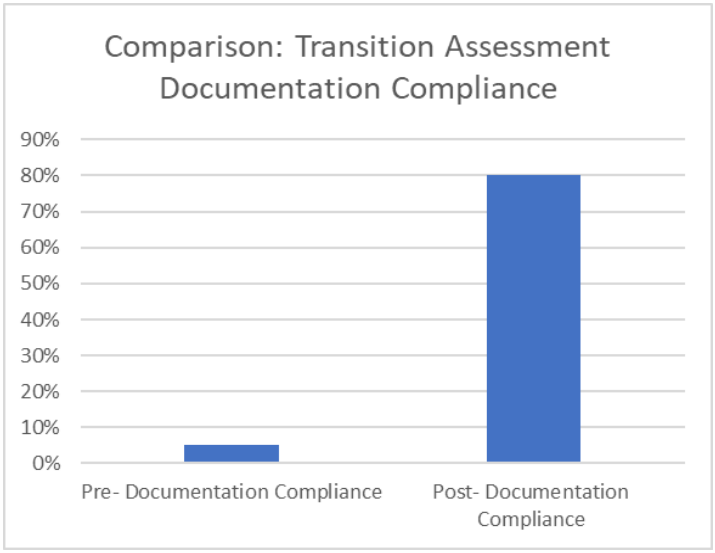
Outcome Goal Results




*Note.* This figure compares the difference in documentation compliance of education topics before (pre) the process improvement to after the process improvement (post). The documentation increased from 5% compliance to 100% compliance.

**Appendix D, continued**

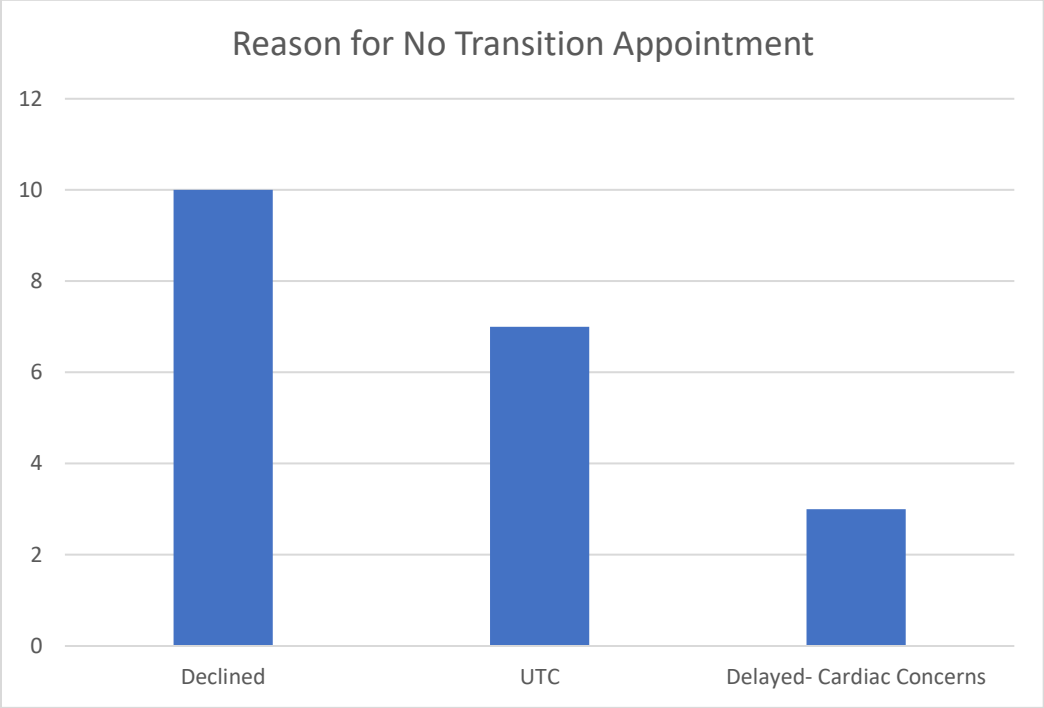
Outcome Goal Results




*Note.* This figure compares the documentation compliance of the transition assessment before the process improvement (pre) compared to the documentation compliance after (post) the process improvement. The compliance rate increased from 5% to 80%.

**Appendix D, continued**

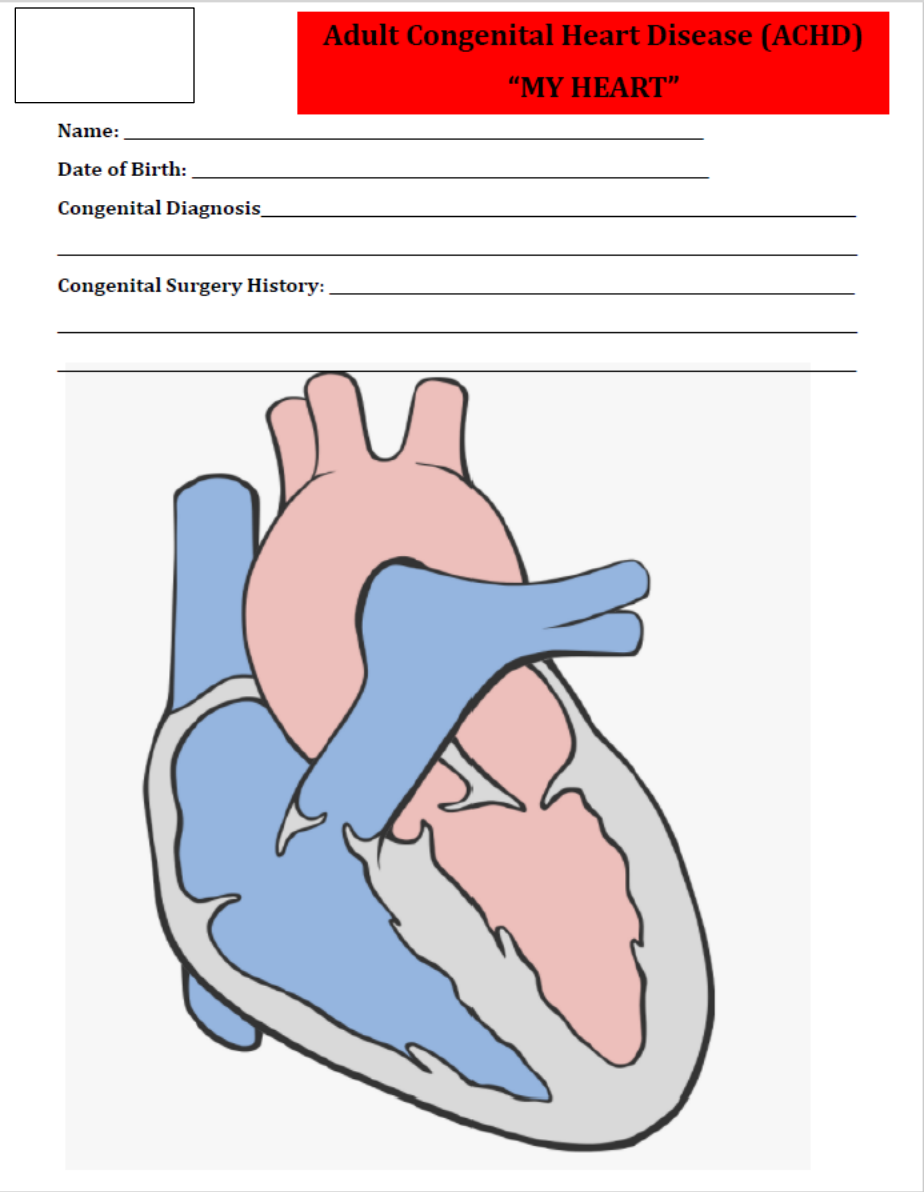
Outcome Goal Results




*Note.* This figure shows the reasons and how many patients gave that reason, for patients who declined or refused a transition appointment.

## Appendix E

My Heart Diagram: Patient Handout




*Note.* This is the "My Heart" handout that the Adult Congenital Heart Nurse Practitioner would use during a transition appointment to give the patient surgical history, diagnosis history, anatomy description, and other necessary information.