

## Congenital Heart Disease

**Developed by:**

American College of Cardiology with input from the American Academy of Pediatrics and the American College of Physicians

**How Developed:** Congenital heart disease is actually comprised of a variety of congenital heart defects that can range from mild conditions requiring only routine follow up and/or medications to severe complex defects requiring multiple operations in infancy and/or the first few years of life. These conditions can be difficult to manage clinically and the management can change over time. As survival to adulthood is >90% for most conditions, this management is further complicated by the need for transition to adult-oriented medical care and care systems over time.

Recognizing the need to improve transition and to enhance care coordination between pediatric and adult practices, the American College of Cardiology spearheaded an initiative to develop pediatric-to-adult transitions of care tools for patients with congenital heart disease. While specific information may vary depending on the particular heart condition, the foundational information for transitions are similar regardless of the complexity of the heart condition. Working groups with experts in pediatric and adult congenital heart disease, as well as patient advocacy groups, family members, and patients, were established to evaluate gaps in care coordination and address needs in these areas. The resulting toolkits provide a comprehensive approach to begin to manage transitions for patients with congenital heart conditions.

Tool Name	Description of Tool	How to Use Tool
<a href="#"><u>Transition Readiness Self-Assessment</u></a> (Pediatric)	An assessment tool intended to be filled out by the youth patient (age 12-17) and utilized by the pediatric cardiac care team to begin the conversation about the skills needed to transition to adult-oriented healthcare. This tool indicates the elements specifically related to transitioning to adult care that should be assessed and documented by the transferring pediatric practice.	This <a href="#"><u>tool</u></a> is intended to be filled out by youth patients (age 12-17) prior to transitioning to an adult congenital healthcare provider and/or assuming independence in his/her own healthcare. The form can be filled out in the waiting area. The tool specifically addresses transition skills and is intended to provide healthcare providers an additional way to evaluate the patient’s transition readiness. This is intended to supplement ongoing conversations and long-term planning. Both the clinic and the patient may keep copies of the assessment.

<p><u><a href="#">General Health Knowledge Assessment for Youth (Pediatric)</a></u></p>	<p>An assessment tool intended to be filled out by the youth patient (age 12-17) and utilized by the pediatric cardiac care team to begin the conversation about the youth’s needed skills to manage his/her health and healthcare. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.</p>	<p>This <u><a href="#">tool</a></u> is intended to be filled out by the youth patient (age 12-17) prior to transitioning to an adult healthcare provider and/or assuming independence in his/her own healthcare. The form can be filled out in the waiting area. The tool specifically addresses skills and knowledge in general healthcare and understanding of the patient’s condition. Both the clinic and the patient may keep copies of the assessment.</p>
<p><u><a href="#">Transition Self-Care Assessment (Adult)</a></u></p>	<p>An assessment tool to be filled out by the young adult patient (age 18-29) and utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal transition from the pediatric practice.</p>	<p>This <u><a href="#">tool</a></u> is intended to be filled out by the young adult patient (ages 18-29) prior to transitioning to an adult congenital healthcare provider and/or assuming independence in his/her own healthcare. The form can be filled out in the waiting area. The tool specifically addresses transition skills and is intended to provide healthcare providers an additional evaluation tool of the patient’s transition readiness. This is to supplement ongoing conversations and long-term planning. Both the clinic and the patient may keep copies of the assessment.</p>

<p><u><a href="#">General Health Knowledge Self-Care Assessment (Adult)</a></u></p>	<p>An assessment tool to be filled out by the young adult patient (age 18-29) and utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).</p>	<p>This <u><a href="#">tool</a></u> is intended to be filled out by the young adult patient (age 18-29) prior to transitioning to an adult healthcare provider and/or assuming independence in his/her own healthcare. The form can be filled out in the waiting area. The tool specifically addresses skills and knowledge in general healthcare and understanding of the patient’s condition. Both the clinic and the patient may keep copies of the assessment.</p>
<p><u><a href="#">Clinical Summary/Transfer Record (Essential Clinical Information)</a></u></p>	<p>A medical record summary to be filled out by the cardiology provider that indicates essential clinical information specifically related to the clinical condition that is to be included in the patient’s medical record upon transfer to the adult congenital cardiology practice.</p>	<p>This <u><a href="#">form</a></u> is to be filled out by the pediatric or general adult cardiology provider to aid the transition process to adult congenital cardiology care. It is intended to be shared with the adult congenital healthcare provider during the transfer of medical records and patient history.</p>