



**Name of Clinical Condition:** *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	Specific Tool Instructions	Link(s)
<i>Transition Readiness Self-Assessment (Pediatric)</i>	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.	<i>This tool 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.</i>	<i>[to be added once finalized documents are uploaded]</i>
<i>General Health Self-Assessment (Pediatric)</i>	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.	<i>This tool 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.</i>	



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<p><i>Clinical Summary/Transfer Record (Essential Clinical Information)</i></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><i>This form 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.</i></p>	<p><i>[to be added once finalized documents are uploaded]</i></p>
<p><i>Healthcare Professional and/or Patient Resources</i></p>	<p>A collection of resources (e.g., web-based links) that might be helpful to the referring healthcare professional and patient regarding the particular clinical condition.</p>	<p><i>[Please list any resources related to the condition that may be of use. Separate resources may be listed for use by the care team and by the patient and/or family/caregivers. This may be links to relevant information on the internet or a separate document with a collection of resources.]</i></p>	<p><i>[to be added once finalized documents are uploaded]</i></p>
<p><i>Other [Fill in name of any additional tools]</i></p>	<p><i>[Fill in description if applicable]</i></p>		