

Congenital Heart Disease Young Adult Transition Policy

Measure Description: This Transition policy metric determines whether or not the institution/clinic has an official transition plan in place for young adults with congenital heart disease (CHD) that is available in print or online

Numerator	<p>A written or electronic transition plan that is officially in place for the institution/clinic. Scoring: 0 (do not have a transition plan) or 1 (have a transition plan)</p> <p>A written or electronic log of patient transition plan demonstrating adherence to at least 4/6 clinical recommendations Scoring: 0 (do not follow at least 4/6 clinical recommendations of the transition plan) or 1 (follow at least 4/6 clinical recommendations of the transition plan)</p>
Denominator	Having a transition plan in place for a cardiology clinic with the listed clinical recommendations that is reviewed/updated on a yearly basis
Period of Assessment	Reporting year
Sources of Data	Printed policy or e-policy in the cardiology clinic

Rationale

Appropriate transition in care is essential for reducing lapses in care when moving from pediatric to adult care. In order to ensure appropriate transition of CHD patients from pediatric to adult care, one must have an official institutional/clinic transition plan in place that can be easily accessed by clinic staff and providers via either a printed document or the internet.

Clinical Recommendation(s)

Transition Plan should include elements of the following:

1. Discussion of transition plan/expectations with parent/guardian and adolescent with CHD
2. Timing of initiation of transition to begin in early to mid-adolescence (age based vs emotionally mature/developmental level vs potential for adult care access), but definitely by 15 years of age.
3. Serial assessment of transition readiness and CHD knowledge of adolescent (should happen several times prior to transition)
4. Meet with the patient independently (ie without their parents) for clinic visits prior to transition and if possible, with a member of the ACHD or adult cardiology team at one of those transition visits.
5. Plan to compose a medical summary for patient to take with them upon transfer to adult provider (such as clinical summary/transfer record from the ACP-
www.acponline.org/pediatric-adult-care-transitions/tools)
6. Plan to schedule first appointment with Adult CHD or Adult Cardiology provider as a part of transition, prior to transfer of care

Special Populations (may require flexibility in the transition period):

1. Cardiology populations beyond those with structural congenital heart disease (heart failure/transplant, complex EP cases with no CHD, etc)
2. Cardiology populations with significant developmental delays/genetic abnormalities

ACC/AHA Guidelines

- The timing of transition should be guided by emotional maturity and developmental level (as opposed to chronological age) for transition planning (*Class I; Level of Evidence C*).
- The adolescent should be engaged in transition planning (*Class I; Level of Evidence C*).
- The pediatric cardiology provider should initiate discussions on transition planning and partner with parents in the process (*Class I; Level of Evidence C*).
- The pediatric cardiology provider should initiate and work together with the adolescent on a transition plan using a transition resource binder and/or health “passport” (*Class I; Level of Evidence C*).
- The pediatric cardiologist should prepare a written adolescent transition plan that includes a cardiac destination (*Class I; Level of Evidence C*).

Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*. 2011;123:1454–1485.

Other guidelines:

Transition, refers to a shift in the responsibility of health care management from the family to the patient. A written health care transition plan, prepared together with the young person and family, is recommended. Parents and providers are important partners in transition and a plan will prompt them to consider future expectations for the adolescent patient. Written transition plans should be prepared several years prior to transfer (e.g., by age 14 years).

Saidi, A., & Kovacs, A. H. (2009). Developing a transition program from pediatric- to adult-focused cardiology care: practical considerations. *Congenital Heart Disease*, 4(4), 204–215.

Attribution

At the level of the practice or clinic

Method of Reporting

Electronic vs paper

Challenges to Implementation

- Buy in from stakeholders- pediatric cardiology providers to have a transition plan in place
- Lack of clinic resources to execute transition plan
- Lack of consensus about what should be included in the transition plan
- Lack of ownership over transition plan/program in the clinic/institution

Congenital Heart Disease Young Adult Transfer Policy

Measure Description: This Transfer Policy metric determines whether or not the institution/clinic has an official transfer policy in place for young adults with congenital heart disease (CHD) available in print or online

Numerator	<p>A written or electronic transfer policy that is officially in place for the institution/clinic. Scoring: 0 (do not have a transfer policy) or 1 (have a transfer policy)</p> <p>A written or electronic log of patient transfer policy demonstrating adherence to at least 3/4 clinical recommendations Scoring: 0 (do not follow at least 3/4 clinical recommendations of the transfer policy) or 1 (follow at least 3/4 clinical recommendations of the transfer policy)</p>
Denominator	Cardiology clinic/institution
Period of Assessment	Reporting year
Sources of Data	Printed policy or e-policy in the cardiology clinic

Rationale

Appropriate transition in care is essential for reducing lapses in care when moving from pediatric to adult care. In order to ensure appropriate transfer of care for CHD patients, one must have an official institutional/clinic transfer policy and plan in place that can be easily accessed by clinic staff and providers via either a printed document or the internet.

Clinical Recommendation(s)

Transfer policy to include:

1. Institution/clinic policy in place regarding age that patients should transfer (with documented explanation if provider deviates from this)
2. A plan to identify an ACHD or appropriate adult cardiologist to assume the role of caretaker for the adolescent with CHD prior to transfer, unless patient is already cared for by an ACHD trained specialist
3. A medical summary to use for transfer of medical information to adult provider (including copies of most relevant patient imaging)
4. Mechanism in place to confirm that the patient did/did not attend first ACHD appointment within recommended time period, as set by referring pediatric cardiologist, and if possible, obtain feedback from the ACHD specialist regarding the effectiveness of the transition and transfer to improve the quality of future handoffs

Special Populations (may require flexibility in the timing of transfer):

1. Cardiology populations beyond those with structural congenital heart disease (heart failure/transplant, complex EP cases with no CHD, etc)
2. Cardiology populations with significant developmental delays/genetic abnormalities

ACC/AHA Guidelines

The goals of a formal transition program are to prepare young adults for transfer of care. *Transfer* refers to the actual point in time at which responsibility for patient care is “handed off” to the adult provider. When deciding on the timing of transfer, 2 important points need to be considered: There should be a policy on timing, and this policy should be flexible. A transfer-of- care letter with relevant medical and psychosocial information and a care plan should be provided to the regional ACHD center in a timely fashion, with a copy for the patient to keep in case the ACHD provider changes. It should comprise a complete medical history that includes diagnoses and previous interventions, a medication list, laboratory values, and other diagnostic studies, as well as information about the patient’s functional status, the tempo of disease progression, and the impact of other comorbidities. Information about psychosocial concerns, end-of-life preferences, the extent of family involvement, and adherence issues should also be communicated if available.

Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*. 2011;123:1454–1485.

Other guidelines:

Transfer of care is typically, although not always, part of a successful transition. Furthermore, the effectiveness of transition can impact whether successful transfer occurs. Ideally, the timing of transfer would be flexible and depends on a patient’s chronological age, medical and developmental status, adherence to therapy, maturity and independence, the preparation and readiness of both patient and family, and the availability of appropriate adult health care providers.

Saidi, A., & Kovacs, A. H. (2009). Developing a transition program from pediatric- to adult-focused cardiology care: practical considerations. *Congenital Heart Disease*, 4(4), 204–215.

At the level of the practice or clinic

Method of Reporting

Electronic vs paper

Challenges to Implementation

- Lack of location/place to transfer to (rural setting/no nearby ACHD provider) to facilitate policy
- Lack of buy in from providers for a transfer policy
- Difficulty in making/keeping/passing along medical transfer plan to ACHD provider or adult cardiologist