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	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) 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)
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)

<u>Transition Plan should include elements of the following:</u>

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

<u>Special Populations (may require flexibility in the transition period)</u>:

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