

Sickle Cell Disease

Developed by:

American Academy of Pediatrics
 American College of Physicians
 American Society of Hematology

How Developed: Certain hematologic conditions can be complex and challenging for patients to successfully manage, especially when transitioning to a new health care team. Recognizing the need to improve this transition process and to enhance care coordination between practices, the American Society of Hematology (ASH) spearheaded an initiative to develop pediatric-to-adult transition of care tools for a variety of hematologic conditions. ASH assembled a working group that included pediatric and adult hematologists who treat the spectrum of benign and malignant hematologic conditions to evaluate gaps in care coordination and to begin addressing needs in these areas. The group also included a psychologist who has expertise in hematology and transition programs. The ASH products were reviewed by ASH’s Committees on Quality and Practice, as well as the Society’s Officers. The resulting toolkit provides a comprehensive approach to successfully managing transitions for patients with various hematologic conditions, the toolkit includes generic templates for all hematologic conditions, with an addendum that includes links to additional condition-specific guidelines and resources; (2) specific templates for sickle cell disease (SCD); and (3) specific templates for hemophilia.

Tool Name	Description of Tool	How to Use Tool
<u>Sickle Cell Disease Transition Readiness Assessment</u>	<p>This assessment tool is intended for use by both adolescents and adults for the following purposes:</p> <p>For Adolescent Patients The tool should be used for the pediatric care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage his/her hematologic health and health care. 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>form</u> should be completed by the patient. It is suggested to help assess the teen/emerging young adult’s knowledge and skills regarding his/her sickle cell disease and its management. The tool is intended as an aide to help assess the readiness of older teens/emerging young adults in the transition and to be transferred from pediatric to adult sickle cell providers.</p>

<p><u>Sickle Cell Disease Transition Readiness Assessment</u></p>	<p>This assessment tool is intended for use by both adolescents and adults for the following purposes:</p> <p>For Adult Patients This tool should be 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>form</u> should be completed by the patient. It is suggested to help assess the teen/emerging young adult’s knowledge and skills regarding his/her sickle cell disease and its management. The tool is intended as an aide to help assess the readiness of older teens/emerging young adults in the transition and to be transferred from pediatric to adult sickle cell providers.</p>
<p><u>Sickle Cell Disease Clinical Summary</u></p>	<p>A medical record summary that indicates essential clinical information specifically related to sickle cell disease that is to be included in the patient’s medical record upon transfer to the adult practice.</p>	<p>The clinical summary/transfer record <u>form</u> should be completed, signed, and dated on the last page by the referring provider and patient. The patient and family should review and give the completed form to the new adult health care provider.</p>