

Systemic Lupus Erythematosus (SLE)

Developed by:

American College of Rheumatology

How Developed: The American College of Rheumatology (ACR) Special Committee on Pediatric Rheumatology formed a working group that consisted of adult, med/peds and pediatric rheumatologists, pediatric health professionals as well as a parent and a patient. Patience White, MD, MACR, who works with GotTransition also served as an advisor. The working group selected JIA and SLE as the diseases to develop transition tools for and divided into two areas: pediatric practice tools and adult practice tools. The tools developed were reviewed and approved by the Working Group, the Special Committee on Pediatric Rheumatology and the ACR board of directors.

Tool Name	Description of Tool	How to Use Tool
Pediatric Rheumatology Transition Policy Template	This transition policy electronic template is to be modified by the pediatric rheumatology care team and distributed to patients and families in order to provide information about the practice's approach to transition of care.	The pediatric rheumatology team is to edit this document, put the document on letterhead, and distribute to patients and families in order to acquaint them with the practice's transition policies. This document is to be provided to patients and families at the age determined to be appropriate by the treating provider.



Transition Readiness
Assessment (for Pediatric
Rheumatology Provider)

- TRAQ:
 PDF Version
 Web Version
- GotTransition Readiness Assessment

The transition assessment tools listed here are intended to be used by pediatric rheumatology providers to assess adolescents' and young adults' knowledge about and ability to perform skills needed to manage their health and health care.

These tools are to be used at intervals determined by the pediatric rheumatology provider to assess transition readiness over time and the responses can be used to guide discussions about selfmanagement.

While other transition tools are available (additional link to these?), the tools presented here are currently the only ones validated, available in English and Spanish, and compatible with billing under CPT code.

These tools are not specific to a particular disease state, are available in English and Spanish. Use of these tools in clinical practice can be billed under CPT code 99420 (scoring of instrument required).

The Transition Readiness
Assessment Questionnaire
(TRAQ, version 5.0 – PDF and
Web versions) is a 20 question,
validated, patient-reported
questionnaire. The adolescent
or young adult completes the
survey. The survey is scored by
the provider. The provider
discusses the survey responses
with the patient and family.

The GotTransition transition readiness assessment is also a patient-reported questionnaire. The adolescent or young adult completes the survey. The survey is scored by the provider. The provider discusses the survey responses with the patient and family.

Both tools are to be completed at ages and intervals determined by the treating provider.



Colf Accessment for Voice	This salf assassment to alice to	This tool is to be assembled by
Self-Assessment for Young	This self-assessment tool is to	This <u>tool</u> is to be completed by
<u>Adult with Rheumatic Disease</u>	be completed by the young	the young adult transitioning
	adult transitioning into an adult	into the adult rheumatology
	rheumatology practice. The	practice. The young adult
	adult rheumatology can use this	completes the survey. The
	tool to assess any remaining	provider scores the survey and
	gaps in self-care knowledge and	discusses the survey responses
	skills or additional issues that	with the patient. This tool is to
	need to be addressed to ensure	be completed at intervals
	optimal management of the	determined by the treating
	young adult with JIA.	provider.
	_	
	This tool is to be used at	
	intervals determined by the	
	adult rheumatology provider.	
	Responses can be used to guide	
	discussions about self-	
	management.	
	management.	
	Use of this tool in clinical	
	practice can be billed under CPT	
	code 99420 (scoring of	
	instrument required).	
SLE Medical Summary	This medical record summary	This medical summary is to be
<u>SEE MEdical Sulfilliary</u>	that includes essential	completed by the pediatric
	information specifically related	rheumatology care team, with
	to SLE that is to be included in	input from patient and family.
		At the time of transfer to adult
	the patient's medical record	
	upon transfer to the adult	rheumatology, this transfer can
	practice.	accompany the medical
		information sent to the adult
		rheumatologist assuming care
		of the young adult.



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<u>Transfer Letter</u>	This letter serves as a brief introduction about the patient for the adult rheumatologist who is assuming care. This letter is to accompany the JIA Medical Summary and other medical information sent to the adult rheumatologist.	This transfer letter electronic template is to be modified by pediatric rheumatology practices and tailored to the individual patient. It is helpful for the pediatric rheumatologist to include personal information which will help the adult rheumatologist engage the young adult. For example, "Joy is a talented bass player, enjoys playing soccer and plans a career in business."
Adult Rheumatology Practice Welcome Letter	This letter is intended to welcome the young adult to the adult rheumatology practice and inform the young adult about key information concerning the adult rheumatology practice.	This <u>electronic template</u> is to be modified by the adult rheumatology practice and distributed to young adults who integrating into the practice.
Healthcare Professional and Patient/Family Resources	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.	This <u>list</u> of online rheumatology and other transitions resources is intended for use by healthcare professionals, patients, and families.
Top 5 Things for an Adult Rheumatologist to Know about Childhood-onset SLE	This succinct document is meant to provide key information to adult rheumatology and primary care providers about important concerns in a young adult with SLE.	Pediatric rheumatology providers can include this information in transfer packet sent to the adult rheumatologist assuming care. Adult rheumatology and primary care providers can also access this information via the ACR website.