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.

<table>
<thead>
<tr>
<th>Tool Name</th>
<th>Description of Tool</th>
<th>How to Use Tool</th>
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<tbody>
<tr>
<td><strong>Pediatric Rheumatology Transition Policy Template</strong></td>
<td>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.</td>
<td>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.</td>
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### 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 self-management.

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).

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The GotTransition 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.
| **Self-Assessment for Young Adult with Rheumatic Disease** | This self-assessment tool is to be completed by the young adult transitioning into an adult rheumatology practice. The adult rheumatology can use this tool 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 young adult with JIA. This tool is to be used at intervals determined by the adult rheumatology provider. Responses can be used to guide discussions about self-management. Use of this tool in clinical practice can be billed under CPT code 99420 (scoring of instrument required). | This tool is to be completed by the young adult transitioning into the adult rheumatology practice. The young adult completes the survey. The provider scores the survey and discusses the survey responses with the patient. This tool is to be completed at intervals determined by the treating provider. |
| SLE Medical Summary | This medical record summary that includes essential information specifically related to SLE that is to be included in the patient’s medical record upon transfer to the adult practice. | This medical summary is to be completed by the pediatric rheumatology care team, with input from patient and family. At the time of transfer to adult rheumatology, this transfer can accompany the medical information sent to the adult rheumatologist assuming care of the young adult. |
### Transfer Letter
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 electronic template 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 list 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.