

End-Stage Renal Disease (ESRD)

Developed by:

*Renal Physicians Association
 American Association of Kidney Patients
 American Society of Pediatric Nephrology
 American Society of Nephrology
 National Forum of ESRD Networks*

How Developed: The nephrology workgroup focused on identifying and refining existing tools related to ESRD -- for patients transitioning to both dialysis (including hemodialysis, peritoneal dialysis, and home hemodialysis) and transplantation. The workgroup included both adult and pediatric nephrologists and patient representatives. The following members of the nephrology workgroup support the policy statement found in Transition from Pediatric to Adult Renal Services: a [Consensus Statement](#) by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA) (KI (2011) 80, 704-707): RPA, AAKP, ASPN, and the Forum. The statement identifies five points to ensure quality care. The statement also suggests procedures for implementing the policies.

Tool Name	Description of Tool	How to Use Tool
<p>Transition Readiness Assessment Scale (Adolescents/Young Adults)</p> <ul style="list-style-type: none"> • English Version • Spanish Version 	<p>An assessment tool intended to be utilized by the pediatric nephrology care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage their health and health care. This 10-domain, 32-item questionnaire is administered (in person or by phone) by a trained professional in about 7-8 minutes. Each response is scored individually as either 1 (adequate knowledge/skill mastery), 0.5 (some knowledge/skill attainment), and 0 (no knowledge/skill attainment) for a maximum score of 10.</p> <p>Available in English and Spanish.</p>	<p>Read the question to the patient, and circle the choice on the right that best describes the patient’s response. Sum the scores for each section in the “Subtotal” row.</p> <p>Not all questions may be applicable to each patient.</p> <p>Divide the subtotal by the number of applicable questions in each section to obtain the “Proportion.”</p>

<p><u>Transition Readiness Assessment Scale (Parent/Caregiver)</u></p> <ul style="list-style-type: none"> • <u>English Version</u> • <u>Spanish Version</u> 	<p>An assessment tool intended to be utilized by the pediatric nephrology care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage their health and health care. This 10-domain, 32-item questionnaire is administered (in person or by phone) by a trained professional in about 7-8 minutes. Each response is scored individually as either 1 (adequate knowledge/skill mastery), 0.5 (some knowledge/skill attainment), and 0 (no knowledge/skill attainment) for a maximum score of 10.</p> <p>Available in <u>English</u> and <u>Spanish</u>.</p>	<p>Read the question to the parent, and circle the choice on the right that best describes the parent’s response. Sum the scores for each section in the “Subtotal” row. Not all questions may be applicable to each parent.</p> <p>Divide the subtotal by the number of applicable questions in each section to obtain the “Proportion.”</p>
<p><u>Transition Readiness Self-Assessment (Adolescents/Young Adults)</u></p> <ul style="list-style-type: none"> • <u>English Version</u> • <u>Spanish Version</u> 	<p>An assessment tool to 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>Available in <u>English</u> and <u>Spanish</u>.</p>	<p>To be completed by the patient. Provide patient with the following instructions:</p> <p>“Patients with chronic health conditions need to have special skills and do special tasks to stay healthy.</p> <p>On the following pages, please check the box underneath the answers that describe you most.</p> <p>If you do not understand a question, just ask for help. We’re here to help you.”</p>

<p><i>Clinical Summary/Transfer Record:</i></p> <ul style="list-style-type: none"> • Transitions Introductory Letter • Transfer Letter Form 	<p>Two part communication tool – the first (optional) is an introductory and educational piece. The second is the medical record summary that indicates essential clinical information specifically related to the clinical condition that is to be included in the patient’s medical record upon transfer to the adult practice.</p>	<p>Two part communication tool:</p> <p>Part 1 (optional but recommended): Transitions Introductory Letter</p> <p>Template for communication: Click where indicated for drop down options. Attach medical records as indicated.</p> <p>Part 2: Transfer Letter</p> <p>Template for communication: Click where indicated for drop down options. Attach medical records as indicated.</p>
<p><i>Healthcare Professional and/or Patient Resources</i></p>	<p>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.</p>	<p>Forum of ESRD Networks Transitions of Care Toolkit: Chapter 9. Healthcare Transition from Pediatric-to Adult-Focused Dialysis Services (available for download here).</p> <p>Transition from Pediatric to Adult Renal Services: a Consensus Statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA) (KI (2011) 80, 704-707) (available here).</p>
<p>Resource List</p>	<p>Comprehensive list of providers and services that will enable the care team to know who to call for assistance with the patients’ needs.</p>	<p>Complete name and contact information for each relevant provider. May be customized to reflect care team.</p>

<i>Medical Passport</i>	This is a portable health summary to be used as a patient education and patient/provider communication tool. It contains medication info – when/why it is prescribed, diagnosis name and allergies. A credit card sized document that is easily carried in one’s wallet.	<i>Pending – To Be Added</i>
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