



OHSU HEALTH SYSTEM OFFICE OF CLINICAL INTEGRATION AND EVIDENCE-BASED PRACTICE

GUIDELINE FOR THE MANAGEMENT OF PEDIATRIC TO ADULT HEALTH CARE TRANSITION

Background: Pediatric to Adult Care Transition (PACT) is the process of transitioning between pediatric and adult models of care. PACT refers to a process that spans many years (usually between the ages of 12-26), and includes important milestones related to advancing readiness to assume self-care, improved disease self-management skills, legal changes in decision-making rights, consent for health care, and privacy and access to information. It is imperative that all adolescents and young adults (AYA) proceed through the transition process with an effort towards fostering self-management and self-advocacy to ensure success within the adult model of care.

Importantly, this process may involve a transfer in primary care providers, specialty providers, or both, and when this transfer occurs, data suggests that patients experience increased disease exacerbation events, decreased satisfaction with care, and the health care system incurs higher overall costs of care. For patients with intellectual disability, neurodevelopmental disorders, or multi-system chronic conditions of childhood, the PACT period is particularly vulnerable and additional issues such as establishment of a supported decision making plan or guardianship status may need to be considered and documented appropriately.^{1,2}

A coordinated PACT process requires the input and active involvement of a robust interprofessional and multidisciplinary team, to contribute to the preparation, education, and coordinated transfer of care for each AYA. These guidelines describe the primary components of an effective PACT process, focusing on patients in the ambulatory care setting.^{1,2}

Prevalence: Over 2,000 unique preventive visits for patients ages 12-22 were completed in general pediatric

practices at OHSU in 2018. This does not include other medical homes, specialty care, or patients for whom no preventive visit is coded.

Risks: Many studies of specific AYA populations have consistently shown that the AYA period is associated with lower ambulatory care setting utilization, increased disease exacerbations, increased ED visits, and hospitalizations. Examples include: increased admissions for diabetic ketoacidosis, increased IBD exacerbations, increased rejection of kidney transplants.

Definitions:

Pediatric to Adult Care Transition (PACT): the process of moving from a child to an adult model of health care with or without a transfer to a new clinician.

Adolescent and Young Adult (AYA): a patient who is generally between the ages of 12-26

Parent/Caregiver (CG): a parent, caregiver, supporter, medical decision maker, or guardian who has a legal right to be involved in the AYA's care and assist with or make medical decisions.

Transfer: the actual transfer of care responsibility from one provider to another. This term should be used distinctly from 'Transition' which refers to the entire process.

Guideline Eligibility Criteria: OHSU Ambulatory patients, ages 12-26, in primary care or specialty clinics

Guideline Exclusion Criteria:

- None



Clinical Practice Recommendations:

Integrated care among pediatric and adult primary and specialty care is essential in preparing AYA/CG for the pediatric to adult transition, including transition planning, transfer of care, and integration into adult care.¹⁻³ **(Strong Recommendation; Low Quality Evidence)**

The following components are recommended as part of a robust and successful transition process:

- Designate a Transition Champion to assist AYA in navigating changes in health care.¹⁻¹⁰ **(Strong Recommendation; Low Quality Evidence)**
- Electronically document a transition plan that is accessible to users across the health care system, with contributions from clinician team members.^{1-3, 11-14} **(Conditional Recommendation; Very Low Quality Evidence)**

Practice Implication

-Recommendations apply to the comprehensive care team including all clinicians involved in patient's care such as Pediatrics, Primary Care, Specialty Care, Nursing and Social Work.

Transition Planning

Conduct regular transition readiness assessments appropriate for each clinical setting, beginning in early adolescence to identify gaps in knowledge related to medical conditions, self-care, and use of the health care system with AYA/CG. ^{1-3, 15-26} **(Strong Recommendation; Low Quality Evidence)**

Jointly develop transition-related goals and prioritized actions with AYA/CG, and document regularly in a plan of care. Transition planning should be based on AYA's needs and readiness, and should be developmentally appropriate.¹⁻³ **(Consensus-adapted)**

Changes in decision-making rights, consent, and privacy should be addressed for all AYA/CG. Education and vocational training, community inclusion, independent living, supported decision making, guardianship, and power of attorney should be addressed as appropriate for each AYA's specific situation.²⁻⁻³ **(Consensus-adapted)**

Transition Planning includes the following activities:¹ **(Consensus-adapted)**

- Identify and track patients who are eligible to receive transition services
- Develop and regularly update the plan of care electronically, including readiness assessment findings, medical summary and emergency care plan, and, if needed, legal documents.
- Develop a list of action items and goals to guide the AYA/CG's inter-visit PACT preparation work.
- Prepare AYA/CG for legal changes in decision-making, consent, privacy, and access to information.
- Determine level of need for decision-making supports for AYA with intellectual disabilities and make appropriate referrals.
- When primary and subspecialty care are involved, all members of the medical team should collaborate with each other and the AYA/CG about timing of transfer(s) Provide connections to insurance resources, and appropriate community supports.



Transfer Support

The transition champion in each clinic setting should offer PACT support to AYA/CG prior to and after transfer.¹⁻¹⁰ **(Strong Recommendation; Low Quality Evidence)**

Utilize a medical summary in the transfer process to facilitate accurate, comprehensive, and timely communication among clinicians. This summary is ideally accessible electronically and available to all care team members (interprofessional and multidisciplinary), and includes information about medical history, medications, emergency care plan, and lists all providers involved in the AYA's care.^{1-3, 11-14} **(Conditional Recommendation; Very Low Quality Evidence)**

Collaborate with AYA/CG regarding the age for transfer .^{1-3, 27} **(Strong Recommendation; Low Quality Evidence)**

Transfer Support includes the following activities:¹ **(Consensus-adapted)**

- Assist AYA/CG in identifying an adult provider if needed.
- Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.
- If appropriate, ensure that legal medical decision maker, supported decision making process, and information authorization is documented in medical record with supporting documentation
- Ensure that AYA/CG are aware of legal changes in decision-making, consent, privacy, and access to information.
- Send transfer package to adult practice, and confirm adult practice's receipt of transfer package.

Practice Implication

Within some clinics, patients are able to remain with the same health care provider from childhood to adulthood. These patients will still experience a transfer from the pediatric to the adult model of care, even when remaining with the same provider. For these patients and families, it is important to clearly outline the differences in the models of care as AYA reach the age of independent decision-making and consent. Patients remaining with the same provider will not need as much documentation and support from champions as those patients transferring between pediatric and adult providers

Transfer Completion

Pediatric clinicians should continue to offer consultation assistance to adult providers, as needed.¹ **(Consensus-adapted)**

Verify that patient transitioned to adult setting after scheduled adult clinic appointment.¹⁻³ **(Consensus-adapted)**

Adult clinical settings should be oriented to care and management of AYA. **(Consensus)**

Adult-oriented providers and practices should engage with the AYA/CG and recognize the developmental differences of a young adult compared to adults of other age groups. **(Consensus-adapted)**

Adult-oriented providers and practices should be prepared to engage with family members and other support persons, particularly for patients with complex diseases originating in childhood. **(Consensus-adapted)**



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Adult-oriented providers and practices should undertake their own self-management assessments for baseline information about AYA/CG knowledge of self-management practices if a prior assessment has not been completed in a pediatric-focused setting. **(Consensus-adapted)**



Quality Measures:

- Structure
 - Designation of transition champion(s)
 - Integration of documentation into EHR
- Process
 - Utilization of readiness assessments
 - Adult care providers identified
 - Number of transfers to adult care
- Outcomes
 - Decreased ED utilization and hospitalization
 - Shorter time between pediatric and adult provider visit
 - Improved medication adherence and chronic disease management (A1c, PFTs, etc)
 - Improved patient, family, provider satisfaction



Integrated care plan:
Designate transition champion and electronically document transition plan

Transition Planning

- * Complete regular readiness assessments to identify needs for self-management
- * Develop goals in collaboration with AYA
- * Create pediatric to adult care transition (PACT) plan including medical summary and discuss legal changes in decision making and consent

Transfer Support

- * Offer PACT support to AYA prior to and after transfer
- * Complete transfer package including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan. If needed, legal documents, conditional fact sheet and additional clinician records

Transfer Completion

- * Verify patient transitioned to adult care after scheduled clinical appointment
- * Adult practice oriented to care and management of AYA
- * Pediatric clinicians should continue to offer consultation assistance

Transfer age dependent on patient readiness and needs

References

1. Got Transition: Six Core Elements of Health Care Transition (2017). Accessed May 14, 2019 at <https://www.gottransition.org/index.cfm>.
2. White, P. H. and W. C. Cooley (2018). "Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home." *Pediatrics* **142**(5): e20182587.
3. National Institute for Health and Care Excellence (2016). "Transition from children's to adults' services for young people using health or social care services." Accessed May 14, 2019 at <https://www.nice.org.uk/guidance/ng43>.
4. Campbell, F., et al. (2016). "Transition of care for adolescents from paediatric services to adult health services." *Cochrane Database of Systematic Reviews* **4**: Cd009794.
5. Gabriel, P., et al. (2017). "Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review." *The Journal of Pediatrics* **188**: 263-269.e215.
6. Mackie AS, Islam S, Magill-Evans J, Rankin KN, Robert C, Schuh M, Nicholas D, Vonder Muhll I, McCrindle BW, Yasui Y, Rempel GR. (2014). "Healthcare transition for youth with heart disease: a clinical trial." *Heart*, 100(14):1113-8. doi: 10.1136/heartjnl-2014-305748. Epub 2014 May 19. PMID:24842870
7. Disabato, J. A., et al. (2015). "Transition from Pediatric to Adult Specialty Care for Adolescents and Young Adults with Refractory Epilepsy: A Quality Improvement Approach." *Journal of Pediatric Nursing*, 30(5): e37-45. doi: 10.1016/j.pedn.2015.1006.1014. Epub 2015 Aug 1018.
8. Seeley A, Lindeke L. (2017). "Developing a Transition Care Coordination Program for Youth With Spina Bifida." *Journal of Pediatric Health Care*, 31(6):627-633. doi: 10.1016/j.pedhc.2017.04.015. Epub 2017 Jul 29. PMID:28760316
9. Levy-Shraga, Y., et al. (2016). "Glycemic control and clinic attendance of emerging adults with type 1 diabetes at a transition care clinic." *Acta Diabetol.* **53**(1): 27-33. doi: 10.1007/s00592-00015-00734-z. Epub 2015 Mar 00522.
10. Lemke, M., et al. (2018). "Perceptions of health care transition care coordination in patients with chronic illness." *Pediatrics*, **141**(5): 1-8. doi: 10.1542/peds.2017-3168.
11. Abraham, J., Kannampallil, T., & Patel, V. L. (2014). A systematic review of the literature on the evaluation of handoff tools: implications for research and practice. *Journal of the American Medical Informatics Association : JAMIA*, 21(1), 154–162. doi:10.1136/amiajnl-2012-001351
12. Wiemann, C. M., Hergenroeder, A. C., Bartley, K. A., Sanchez-Fournier, B., Hilliard, M. E., Warren, L. J., & Graham, S. C. (2015). Integrating an EMR-based Transition Planning Tool for CYSHCN at a Children's Hospital: A Quality Improvement Project to Increase Provider Use and Satisfaction. *Journal of pediatric nursing*, 30(5), 776–787. doi:10.1016/j.pedn.2015.05.024
13. Sharma, N., et al. (2018). "Care Coordination and Comprehensive Electronic Health Records are Associated With Increased Transition Planning Activities." *Academic pediatrics* **18**(1): 111-118.
14. Zabora, J.R., et al. The Challenges of the integration of cancer survivorship care plans with electronic medical records. *Seminars in Oncology Nursing*, Vol 31, No1. February 2015: 73-78
15. Gilleland, J., et al. (2012). "Getting ready to leave: transition readiness in adolescent kidney transplant recipients." *J Pediatr Psychol* **37**(1): 85-96.
16. Moynihan, M., et al. (2015). "Assessing readiness for transition from paediatric to adult health care: Revision and psychometric evaluation of the Am I ON TRAC for Adult Care questionnaire." *Journal of Advanced Nursing* **71**(6): 1324-1335.



17. Jones, K. E., et al. (2017). "The Kennedy Krieger Independence Scales-Sickle Cell Disease: Executive components of transition readiness." Rehabil Psychol **62**(3): 249-257.
18. Warschausky, S., et al. (2017). "Health self-management, transition readiness and adaptive behavior in persons with cerebral palsy or myelomeningocele." Rehabil Psychol **62**(3): 268-275.
19. Carlsen, K., et al. (2017). "Self-efficacy and Resilience Are Useful Predictors of Transition Readiness Scores in Adolescents with Inflammatory Bowel Diseases." Inflamm Bowel Dis **23**(3): 341-346.
20. Wood, D. L., et al. (2014). "The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity." Academic pediatrics **14**(4): 415-422.
21. Nazareth, M., et al. (2018). "A Parental Report of Youth Transition Readiness: The Parent STARx Questionnaire (STARx-P) and Re-evaluation of the STARx Child Report." Journal of Pediatric Nursing **38**: 122-126.
22. Ferris, M., et al. (2015). "Self-Management and Transition Readiness Assessment: Development, Reliability, and Factor Structure of the STARx Questionnaire." Journal of Pediatric Nursing **30**(5): 691-699.
23. Cohen, S. E., et al. (2015). "Self-Management and Transition Readiness Assessment: Concurrent, Predictive and Discriminant Validation of the STARx Questionnaire." Journal of Pediatric Nursing **30**(5): 668-676.
24. Zijlstra, M., et al. (2013). "Self-efficacy in adolescents with inflammatory bowel disease: a pilot study of the "IBD-yourself", a disease-specific questionnaire." Journal of Crohn's & colitis **7**(9): e375-385.
25. Tung, J., et al. (2015). "Pilot Development of an Electronic Pediatric Inflammatory Bowel Disease Quiz Game." Journal of Pediatric Gastroenterology & Nutrition **61**(3): 292-296.
26. Rosen, D., et al. (2016). "Transition of Inflammatory Bowel Disease Care: Assessment of Transition Readiness Factors and Disease Outcomes in a Young Adult Population." Inflamm Bowel Dis **22**(3): 702-708.
27. Yassae, A., et al. (2019). "The Impact of Age of Transfer on Outcomes in the Transition From Pediatric to Adult Health Systems: A Systematic Review of Reviews." Journal of Adolescent Health **64**(6): 709-720.



Guideline Preparation

This guideline was prepared by Transition Task Force in collaboration with the Office of Clinical Integration (CI) and Evidence-Based Practice (EBP) at Oregon Health and Science University.

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Development Process

This guideline was developed using the process outlined in the CI and EBP Manual (2016). The review summary documents the following steps: 1. Review Preparation - PICO questions established - Evidence search confirmed with content experts 2. Review of Existing Internal and External Guidelines - Literature Review of Relevant Evidence 3. Critically Analyze the Evidence 4. Summarize the Evidence by preparing the guideline, and order sets - Materials used in the development of the guidelines, review summaries are maintained in a Management of Pediatric to Adult Health Care Transition EB review manual with the Office of CI and EBP.

Evaluating the Quality of the Evidence

Published clinical guidelines were evaluated for this review using the **University of Pennsylvania’s Trustworthy Guideline Rating Scale**. The summary of these guidelines are included in the evidence summary. The rating scale is based on the Institute of Medicine’s “Standards for Developing Trustworthy Clinical Practice Guidelines” (IOM), as well as a review of the AGREE Enterprise and Guidelines International Network domains. This scale evaluates a guideline’s transparency,

conflict of interest, development group, systematic review, supporting evidence, recommendations, external review and currency and updates. The purpose of this scale is to focus on the weaknesses of a guideline that may reduce the trust a clinical user can have in the guideline, and distinguish weaknesses in documentation (e.g. guideline does not have a documented updating process) from weaknesses in the guidance itself (e.g. recommendations are outdated).

The **GRADE (Grading of Recommendations, Assessment, Development and Evaluation)** criteria were utilized to evaluate the body of evidence used to make clinical recommendations. The table below defines how the quality of the evidence is rated and how a strong versus conditional recommendation is established. The evidence summary reflects the critical points of evidence.

Recommendation	
STRONG	Desirable effects clearly outweigh undesirable effects or vice versa
CONDITIONAL	Desirable effects closely balanced with undesirable effects
Quality	Type of Evidence
High	Consistent evidence from well-performed RCTs or exceptionally strong evidence from unbiased observational studies
Moderate	Evidence from RCTs with important limitations (e.g., inconsistent results, methodological flaws, indirect evidence, or imprecise results) or unusually strong evidence from unbiased observational studies
Low	Evidence for at least 1 critical outcome from observational studies, from RCTs with serious flaws or indirect evidence
Very Low	Evidence for at least 1 critical outcome from unsystematic clinical



	observations or very indirect evidence
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Recommendations

Recommendations for the guidelines were directed by the existing evidence, content experts, and consensus. Patient and family preference were included when possible. When evidence is lacking, options in care are provided in the guideline and the order sets that accompany the guideline.

Approval Process

Guidelines are reviewed and approved by the Content Expert Team, Office of CI and EBP, Knowledge Management and Therapeutics Committee, Professional Board, and other appropriate hospital committees as deemed appropriate for the guideline’s intended use. Guidelines are reviewed and updated as necessary every 2 to 3 years within the Office of CI and EBP at OHSU. Content Expert Teams will be involved with every review and update.

Disclaimer

Guideline recommendations are made from the best evidence, clinical expertise and consensus, in addition to thoughtful consideration for the patients and families cared for within the Integrated Delivery System. When evidence was lacking or inconclusive, content experts made recommendations based on consensus. Expert consensus is implied when a reference is not otherwise indicated.

The guideline is not intended to impose standards of care preventing selective variation in practice that is necessary to meet the unique needs of individual patients. The physician must consider each patient and family’s circumstance to make the ultimate judgment regarding best care.