Purpose

This document provides guidance on quality assurance (QA) transition practices for adolescents and young adults with or at risk for thrombosis, who are ≥ to 18 years of age and will be transitioned to adult care. The goal of this document is to improve the transition process for these patients. This Quality Assurance Plan highlights the critical components of a quality transition process / program.

Importance of a Quality Assurance Transition Program

Discontinuity of care during the handoff between pediatric to adult providers has been linked to patient, provider, system, and economic factors, including insufficient patient and family preparation, cognitive or psychosocial impairment, patient–provider attachment, inadequate program integration, and poor access to adult specialty care.[7,8]

A planned transition process should begin early in adolescence (ages 12-14 years) for all youth, including those with special health care needs. Starting with a discussion of the practice's policy on transition with youth and parents, the process continues over time to ensure readiness and planning for adult-centered care at age 18 and for transfer to an adult provider. Patient–provider collaboration in the preparation of a personalized health transition plan has been associated with improved health literacy and increased patient participation in their health care.[22] Testing of a patient's specific health knowledge is important for understanding his or her progress toward self-management and identifying areas needing reinforcement. This transition process continues until youth and young adults are integrated into an adult model of care [10]. According to the AAP/AAFP/ACP, transition should be a part of routine specialty care with specific collaborative roles for pediatric, family medicine, and internal medicine practices with well-defined co-ordination of pediatric and adult services.

The guidelines in this document outline the basic elements of a QA program, as it applies to transition of youth and young adults to adult thrombophilia care. Six Core Elements have been identified to guide health care transition.

Six Core Elements for Health Transition

1. Transition Policy
    a. The document will serve as the KIDCLOT transition policy
2. Transition Registration

    a. The KIDCLOT program will maintain a list of all patients requiring follow up who are ≥12 years of age (registration list).
    b. Registered patients will be highlighted on all follow up lists including clinic appointments with the initials "TR" (transition). Once registered, the transition process will be initiated then continuous in all patient follow up.

3. Transition Patient Preparation (transitions, readiness assessment- TRAQ)
    a. Questionnaire will be completed by all children ≥12 years of age who requiring long term follow. In patients where cognitive / functional challenges prohibit the child from completing the survey, a parent-proxy will be completed.
    b. Outpatient nurse will provide questionnaire to patient during each follow up appointment.
    c. Questionnaire will be completed annually.
    d. Care provider (physician or nurse practitioner) will review the completed questionnaire with the patient and family and establish a plan for progression towards self-efficacy to facilitate safe and effective transition by 18 years of age.
4. Transition Plan (action plan)
    a. Patients with thrombophilia
        i. Provide verbal and written education describing their diagnosis.
        ii. Evaluate youth understanding of their health condition and potential risks.
        iii. Establish a transition plan in collaboration with youth.
            1. Determine an appropriate adult physician taking into consideration patient preference.
            2. Provide a written transition plan including frequency of routine follow up and when to seek emergency follow up.
            3. Provide patient the contact information for the adult provider who will provide their adult care.
    b. Patients requiring long term anticoagulation therapy.
        i. Patients performing patient self-management safely and effectively will continue PSM.
            1. Adult care will be provided by Dr. Lauren Bolster or designate.
            2. Patients will continue to report INRs using the KIDCLOT.com website.
            3. Patient will be seen in follow up with 12 months of patient transfer.

    c. Patients not performing PSM or deemed not to be performing PSM safely and effectively will be transferred to either the Adult Anticoagulation Clinic or an appropriate local physician (family doctor) or local anticoagulation clinic taking into consideration patient preference.
    d. PST
        i. Meter ownership
    e. Lab
    f. LMWH
    g. NOACs
5. Transition and Transfer to Adult care (Transition or transfer to adult care checklist, communication with adult provider, and, if needed, shared care with adult provider)
6. Transition Completion (documentation of transfer)

References

American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians (AAP/AAFP/ACP) Clinical Report on Transition from Adolescence to Adulthood