Published in final edited form as:

J Pediatr Nurs. 2015 ; 30(5): 776–787. doi:10.1016/j.pedn.2015.05.024.

Integrating an EMR-based Transition Planning Tool for CYSHCN at a Children's Hospital: A Quality Improvement Project to Increase Provider Use and Satisfaction

Constance M. Wiemann, PhD^{a,*}, Albert C. Hergenroeder, MD^a, Krystle A. Bartley, MA^b, Blanca Sanchez-Fournier, BA^a, Marisa E. Hilliard, PhD^a, Laura J. Warren^c, and Sarah C. Graham, MPH^a

^aDepartment of Pediatrics, Baylor College of Medicine, Houston, TX

^bCenter for Clinical Effectiveness, Baylor College of Medicine, Houston, TX

^cTexas Parent to Parent, Austin, TX

Abstract

An electronic medical record (EMR)-based transition planning tool (TPT) designed to facilitate transition from pediatric to adult-based health care for youth (16–25 years) with special health care needs was introduced at a large children's hospital. Activities to increase provider use were implemented in five plan–do–study–act cycles. Overall, 22 of 25 (88%) consenting providers in four pediatric subspecialty services used the TPT during 303 patient encounters, with nurses and case-managers the top users and physicians the least likely users. Use was highest with intensive technical assistance and following the introduction of an upgraded tool. Provider satisfaction with the TPT and self-reported transition planning activities notably increased across the PDSA cycles.

Keywords

Quality improvement; Electronic medical record; Health care transition planning; CYSHCN; PDSA

Project Overview

Advancements in Medicine have increased the likelihood that US children with chronic illnesses will survive childhood—subsequently 750,000 youth with special health care needs (YSHCN) transition to adulthood annually (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002; Goodman et al., 2011; Scal, Davern, Ireland, & Park, 2008). As the medical condition becomes more convoluted, transition to adult health care also becomes more complex, resulting in increased morbidity and mortality (Annunziato et al., 2011; Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Herish, Pang, Curran, Milojevic, & von Scheven, 2009; Kelly, Kratz, Bielski, & Rinehart, 2002; Okumura, Herish, Hilton, &

*Corresponding author: Constance M. Wiemann, PhD., cwiemann@bcm.edu.

Lotstein, 2013; Quinn, Rogers, McCavit, & Buchanan, 2010). Nevertheless, the expanded emphasis on health care transitions during the past decade has not resulted in measurable improvements in health care transition (HCT) planning (McManus et al., 2013). Therefore, children's hospitals and professional organizations are calling for structures and processes to improve HCT planning for YSHCN and their families (Cooley & Sagerman, 2011; National Association of Pediatric Nurse Practitioners, 2014; Peters & Laffel, 2011; Texas Parent to Parent, 2015). In response to this need, Texas Children's Hospital (TCH) developed a transition planning tool (TPT) that serves two purposes: (1) it evaluates the patient and family condition-specific knowledge and skills and (2) it encourages teachable moments between the provider and patient, which facilitates HCT planning. Rather than developing a paper-based tool, TCH integrated the TPT into Epic, its electronic medical record (EMR). While the use of EMR-based planning tools to facilitate transition by pediatric providers is promising, evidence that providers will use these tools is lacking and worthy of investigation. Following Standards for Quality Improvement Reporting Excellence (Ogrinc et al., 2008), this paper describes steps taken to introduce the TPT and increase its use in four subspecialty services.

Background

Absence of Evidence-Based Guidelines for HCT Planning

HCT from pediatric to adult-based care represents both a vulnerable period and clear opportunity to alter the trajectory of health outcomes; yet, there is substantial evidence that HCT planning is not happening for many YSHCN and their families (Lotstein et al., 2009; Quinn et al., 2010). Guidelines have been developed for HCT planning in the pediatric medical home and the impact of these guidelines on HCT will require evaluation (McManus, Fox, O'Connor, Chapman, & MacKinnon, 2008). Children's hospitals provide care to many YSHCN with complex medical conditions and have the need to establish successful HCT programs. YSHCN with complex conditions are more likely to receive their care in children's hospitals, which often function as a medical home. This care can be fragmented if it occurs across multiple hospital and subspecialty clinic settings. Some hospitals have developed disease-specific HCT (Hankins et al., 2012), rather than large-scale hospital or system-wide implementation. Other hospitals have developed non-categorical HCT clinics that serve as a consultative or transition support service for a variety of conditions (McLaughlin et al., 2013; Woodward, Swigonski, & Ciccarelli, 2012). One limitation of the former approach is that HCT programs within a children's hospital typically operate in silos and for patients with complex medical conditions who are seen by more than one subspecialty; this limits the coordination of HCT planning activities across services. Care coordination has been linked to improved quality of care and cost savings (National Committee for Quality Assurance, 2011).

Barriers to HCT Planning

Pediatric providers suggest a structured transition pathway needs to be built into the overall care plan as a part of routine outpatient visits (Clarizia et al., 2009; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004; van Staa, Jedeloo, van Meeteren, & Latour, 2011). Incorporating HCT planning into a children's hospital is a cultural shift. Many

pediatric providers recognize that their patients are living into adulthood and are concerned about the risk of morbidity/mortality following poorly planned transfer to adult-based care, yet most have no training in HCT planning methods. Providers are looking for mechanisms to help prepare patients for medical self-management and for the cultural differences of the adult care world (Paine et al., 2014; Reiss, Gibson, & Walker, 2005; van Staa et al., 2011). To put these programs in place, institutional support is also needed to facilitate additional time during clinic appointments, staff availability, and financial backing (Clarizia et al., 2009; Scal, 2002; Woldorf, 2007). There is also a lack of adult primary care and specialist providers to whom YSHCN can be referred (Bryant, Young, Cesario, & Binder, 2011; Shaw, Southwood, & McDonagh, 2004). Even when an adult provider is identified, trust and communication between pediatric and adult providers are often sparse (Reiss et al., 2005; Telfair et al., 2004; van Staa et al., 2011). Pediatric providers also lack training in therapeutic termination of their relationship with patients they have cared for long-term, which may impede the formation of new relationships with adult providers (Reiss et al., 2005).

Implementing Technology to Change Provider Behavior

Barriers to health care providers' uptake of practice recommendations are wide-ranging and include low awareness, disagreement or uncertainty, perceived time or resource burden or inconvenience, low access to sufficient resources, uncertainty of impact on patient outcomes or alignment with patient preferences, and low confidence about one's own ability to execute them (Cabana, Rand, Becher, & Rubin, 2001; Cabana et al., 1999; Foy et al., 2002; Klein et al., 2010; Ludwick & Doucette, 2009). Technology-based assistance including automated prompts, decision-supports, and documentation tools programmed into the electronic medical record, are increasingly available and designed to address many of the logistical and care process barriers to changing practice behaviors to align with guidelines (Abraham, Kannampallil, & Patel, 2014). Moreover, such programs have demonstrated efficacy in changing provider behaviors for numerous conditions and practice settings including: pediatric asthma diagnosis and treatment (Shiffman, Freudigman, Brandt, Liaw, & Navedo, 2000), adolescent cervical cancer screening (White & Kenton, 2013), and inpatient medication orders (Eslami, de Keizer, & Abu-Hanna, 2008). However, as with any change in practice, provider uptake and sustained use of these new technologies and tools remain a challenge (Carlfjord, Lindberg, Bendtsen, Nilsen, & Andersson, 2010; de Veer, Fleuren, Bekkema, & Francke, 2011; Doerr, Edelman, Gabitzsch, Eng, & Teng, 2014).

Improvement Methods

The primary purpose of this paper is to describe the process of applying improvement science techniques to increase provider use of an EMR-based health care TPT in four subspecialty services of a large children's hospital. A second purpose is to describe provider satisfaction with the TPT and self-reported transition planning activities. The design of this project adheres to the Institute for Healthcare Improvement's Model for Improvement (<http://www.ihl.org/resources/Pages/HowtoImprove/default.aspx>). Improvement methodology emphasizes small tests of change, swift identification and response to problems, context considerations, and a lower threshold for instituting change.

Forming the Team

Investigative Team

The multi-disciplinary team of investigators and staff undertaking this project includes an adolescent medicine physician who has been a member of the TCH Transition Committee since 2004, two psychologists, a project manager from Baylor College of Medicine's Center for Clinical Effectiveness, the parent of a YSHCN who attends weekly project meetings, a transition project manager and a transition research coordinator.

Setting

TCH is the largest pediatric hospital in the United States with more than 40 medical and surgical outpatient services. The TCH Integrated Delivery System sees more than 2 million visits annually and a total of 247 youth with chronic health conditions are eligible to transition from TCH to adult-based care on any given day.

Four subspecialty clinics demonstrated a significant need for transition planning based on their patients' medical complexities and life-expectancy. The patients in those clinics are receiving care for congenital heart disease, sickle cell disease, HIV/AIDS, or neurologic conditions requiring physical medicine and rehabilitation. For the sake of anonymity, those clinics are randomly referred to as clinics A, B, C, and D in this paper.

Participants

The Baylor College of Medicine Institutional Review Board for Human Subjects Research approved this QI initiative. Twenty-five health care providers (physicians, nurses, social workers, and case managers) consented to participate in the quality improvement project and provided basic demographic information (gender, discipline, and numbers of years since completing formal training; see Table 1).

A subset of TCH patients treated by the four subspecialty services were enrolled in a separate study on HCT planning; those treated by providers participating in the current QI study were eligible for initial TPT use. These study subjects were: 16–25 years with a special health care need, aware of his/her diagnosis, English speaking, and able to understand and answer questions. The target enrollment was 30 patients per service. Study patients were recruited between February 2012 and March 2013. Of the 143 patients approached as they attended a scheduled clinic appointment, 109 agreed to participate (34 declined),—with 28 patients from clinic A, 24 from clinic B, 36 from clinic C, and 21 from clinic D.

Planning the Intervention

Aim

The aims of this project are to: 1. increase provider use of a transition planning tool (TPT); 2. understand providers' satisfaction with the TPT; and 3. enhance provider self-report of transition planning activities.

The Intervention

Given the large number of patients eligible for transition who are treated at TCH annually, it was important to understand the barriers and facilitators to successful transitions. The research team crafted a fishbone diagram to identify potential areas of improvement. A 2006 needs assessment of HCT protocols uncovered that 13 TCH subspecialty clinics were accepting new patients (between the ages of 16 and 25) into the clinical services; 9 out of 13 clinics (69%) reported that they routinely transitioned patients to adult providers; 6/13 clinics (46%) identified an adult provider to whom they referred; 1/13 clinics (8%) had a formal HCT protocol; and, 10/13 clinics (83%) wanted help in developing a HCT protocol. For many providers with YSHCN in their practice, the need for a HCT planning program was evident. In addition, data collected through a survey of 91 TCH patients ages 11–23 and 75 of their parents found that only 12% of patients and 10% of parents report achieving the core transition outcome (Hergenroeder, Wiemann, Bowman, & Flanagan, 2012), as defined by Lotstein et al. (2009) (discussions with their health care provider about future adult health care needs; finding an adult provider; securing health insurance; and encouraging young adult patients to take more responsibility for their care).

It became evident that TCH needed one unifying strategy to improve HCT and the TCH transition committee prioritized the development of a transition planning tool. The team conducted systematic literature reviews to find scientifically validated instruments or nationally endorsed tools. A TPT was developed in 2005 after two rounds of input from the hospital's Family and Youth Advisory Boards. All questions were vetted through parent staff at Texas Parent to Parent, a statewide peer support organization for parents of children and youth with special health care needs. The resulting TPT is an assessment and education tool designed to facilitate HCT over the course of clinic visits. The tool was originally designed using specific questions for younger, middle and older adolescents, with the degree of complexity increasing across those age groups. However, we found that the most complex question asked the patient about his/her disease/disability, and that question had to be answered by all patients regardless of age. Thus, to simplify the tool we eliminated the age stratification.

The TPT directly or indirectly addresses five of the six core transition support indicators set forth by Got Transition, a federally funded health care transition resource center (Got Transition/Center for Health Care Transition, 2014). The TPT has 13 core questions that can be asked by the provider in any order. Questions such as “Can you tell me about your disease/disability?” and “What are the names of your medications? What are they for? When do you take them? How much do you take?” are intended to guide the interaction between the provider and the YSHCN. The respondent will either answer the question adequately or require training. Training occurs in a three-pronged strategy: an explanation of the answer is given, homework is provided, and a re-exam occurs at subsequent visits. For most TPT questions, attendant educational support materials were created to assist patients master the content and skills, as needed. The ideal time frame for addressing each question has not been established, but successful HCT planning could be accomplished over the course of a single or several medical visits up to several years prior to transfer to adult care. The time frame depends in part on the patient as some older, more mature and transition-ready patients

completed all 13 questions in one visit, while others answered one question per visit. A subset of questions is available to use with parents/caregivers whose children are developmentally unable to participate. The TPT also allows providers to document HCT preparation across services. More information on the TPT is available upon request. Epic users can access the TPT at the following link, using their name and password: <https://galaxy.epic.com/?#Browse/page=1!68!600!1733006>.

Studying the Intervention

Measures

TPT Utilization—Utilization of the TPT was the primary outcome measure. Data were generated by tallying the number of encounters with TPT use (which includes face-to-face clinic visits and phone encounters) among age eligible study and non-study patients. TPT use data were reported in aggregate by clinic and provider, thus IRB approval for the non-study patients was not required.

Provider Satisfaction and Self-reported Transition Planning Activities

Provider satisfaction and self-reported transition planning activities were secondary outcomes assessed by a survey administered in three different phases of the project. Satisfaction items were developed for this project using instruments from published studies on promoting EMR use (Rose et al., 2005; Sittig, Kuperman, & Fiskio, 1999). Providers used a 5-point scale (“very satisfied” to “very dissatisfied”) to report their satisfaction with items listed in Table 2. Additional open-ended questions asked about barriers to use and suggestions for improvement.

Each survey also asked providers to evaluate a set of transition planning activities adapted from the Family-Centered Care Self-Assessment Tool (Family Voices, 2008). Using a rating scale of “never,” “some of the time,” “most of the time,” and “always,” providers responded to the prompt “Since starting to use the TPT, how often do you...” Additional items added based on discussions with content experts and reviewing literature (Lotstein, McPherson, Strickland, & Newacheck, 2005; Lotstein et al., 2009; Sawicki et al., 2011). All items are included in Table 3. On the first survey, providers provided a second set of responses using the same rating scale and the prompt “Looking back, prior to starting to use the TPT, how often did you...” A retrospective pretest was used because when compared to traditional pre/post self-assessments, retrospective pre/post ratings provide more sensitive and valid measures (Howard et al., 1979; Skeff, Stratos, & Bergen, 1992) and have been successfully used to evaluate interventions for health professionals (Khanna, Cheyney, & Engle, 2009; Laird-Fick et al., 2011; Yank, Laurent, Plant, & Lorig, 2013).

Improvement Cycles—Five plan–do–study–act (PDSA) cycles, used to promote and evaluate the main outcome measure, TPT utilization, were carried out over the 35-month study.

The PDSA, an improvement science method, is a strategy for “developing, testing and implementing changes that should lead to improvement” (Deming, 1994). In each PDSA cycle, the objective is identified and a plan is developed to test the change (plan), the test is

carried out (do), while collecting data throughout the process. The data from the test are examined and compared to benchmarks (study). Changes are then planned or implemented for the next cycle of change (act).

The investigative team reviewed weekly Epic-generated TPT use reports across the four subspecialty clinics. This yielded the number of patient encounters with use and the number of providers using the TPT. Qualitative information gathered during provider feedback sessions and from open-ended questions on provider surveys assessing barriers to use and suggestions for improvement were summarized as part of planning for the next PDSA.

PDSA 1 (March 2012–July 2012). Prior to the initiation of this quality improvement project, TCH moved from one EMR platform, Logician, to the current Epic platform. Participating providers requested that training be delayed until clinics became familiar with the new platform. Therefore, PDSA 1 served as the baseline phase for the TPT because no formal education was provided although the TPT was “live” and available for use within Epic. Study patient recruitment began.

PDSA 2 (August 2012–March 2013) served as the formal training phase of the project. The plan for this phase was to promote TPT use by (1) teaching providers how to properly administer the tool, (2) encouraging participants to adopt the TPT by sending a weekly email with a list of upcoming visit encounters with study eligible patients, (3) offering laminated step-by-step instructional cards on how to access the TPT in the EMR, and (4) hosting quarterly meetings to review TPT usage data and discuss enablers and barriers to transition planning. Project staff provided additional training and technical assistance when requested. At the end of PDSA 2, providers completed provider survey #1. Barriers to TPT use identified by providers included lack of time during busy clinics, use of the TPT disrupted their patient flow and not remembering how to use the TPT by the time a study patient became available. Study patient recruitment ended in March 2013.

PDSA 3 (April 2013–November 2013) activities were aimed at increasing the intensity of the TPT technical assistance to trouble-shoot barriers to use. Project staff contacted TPT users in person, via email, phone, or pager to remind them when the TPT could be used on a study patient and visited individual clinics to meet with providers to facilitate TPT use. Monthly clinic team meetings were added in order to address TPT usage barriers. Quarterly provider meetings across all services continued. At the end of PDSA 3, providers completed provider survey #2. Although overall use improved, providers reported that the TPT was difficult to locate in the EMR and cumbersome to use. They also wanted a mechanism that could give them a clear indication of transition planning already completed with each patient.

PDSA 4 (December 2013–April 2014). Based on feedback provided on surveys and during face-to-face meetings, a streamlined, user-friendly upgrade—TPT version 2.0—was developed and made available in PDSA 4. Changes to the TPT included the addition of a transition button on the EMR navigation pane (previously it had been under patient education) to facilitate easy access to the tool, a flow sheet reporting the patient's transition planning progress to facilitate continuity between providers and over time, and a simplified

user interface with fewer clicks needed to access the TPT. Promotion of its use was limited; thus, PDSA 4 served as the baseline measure of TPT 2.0 use with limited technical assistance.

PDSA 5 (May 2014–December 2014) TPT 2.0 became available to the entire TCH enterprise and was promoted as a tool that could now be used with all patients (not just study patients). A user guide was developed and distributed to assist with accessing and navigating the TPT. TCH Epic educators were also trained to use the TPT and to help others troubleshoot usage barriers. A member of the investigative team presented at Pediatric Grand Rounds on transition and demonstrated TPT use. Although seldom utilized, in-person technical assistance was provided to users who requested additional TPT instruction. Provider survey #3 was administered to providers four months into PDSA 5. Despite improved uptake during PDSA 5, providers cited insufficient time to integrate the TPT into clinic workflow as a barrier to optimum TPT use.

Data Analysis

Bar graphs display the number of patient encounters with TPT use for each clinic within each PDSA cycle, differentiating between use with study patients versus all patients (study and non-study) within each of the four clinics. The median numbers of patient encounters with TPT use were compared by provider type (nursing, medicine, social work/case manager and other) and year of graduation (1972–1999 versus 2000–2013) using Mood's Median Test (SPSS version 22). In addition, individual items from the provider surveys were collapsed into percentages of respondents that reported being satisfied (“very satisfied” and “satisfied”) versus not satisfied (all other responses) with aspects of the TPT and “most of the time or always” versus “some of the time or never” for items self-assessing transition planning activities (Monforto, Figueroa-Altmann, Stevens, Thiele, & Ely, 2012). On provider survey #1 (PDSA 2), two sets of percentages for transition planning activities were calculated reflecting activities before and after starting/integrating the TPT into their workflow/current practice to use the TPT. Given the small number of providers and clinics in this pilot study, inferential statistics were not used.

Results

Overall TPT Use

Twenty-five providers were trained to use the TPT over the course of the five PDSAs. Twenty-two (88%) trained providers used the TPT at least once during the study period with a total of 182 unique patients (77 study and 105 non-study) during 303 patient encounters. Among those providers with TPT use, the median number of uses was 8.5 (mean 13.9 $\pm$ 17.5). Clinic-specific, TPT utilization data are presented in Table 4 and Figures 1 and 2. TPT use rates varied by clinic. While clinics A and B integrated the TPT into practice with the largest number of patients, 65 and 77, respectively, clinic A had the highest average number of encounters in which the TPT was used per provider (19.0), followed by clinic C (14.8), clinic B (12.8), and clinic D (3.0). The median number of uses varied by the providers' discipline: six nurses had 102 encounters with use (median = 15.5, range = 3–37), four case managers/social workers had 114 encounters with use (median = 15, range = 5–

79); 30 uses by three others (median = 12.0, range = 2–16); and 60 uses by nine physicians (median = 5.0, range = 1–18). The median number of uses per provider for those who graduated in 1972–1999 versus 2000–2013 was 5.5 and 10.0, respectively. Using Mood's median test, there were no significant differences in the median number of encounters with use by user discipline or year of graduation. Of note, the number of uses may be an underestimate of actual use as providers new to using the tool often reported forgetting to save their documentation after the first few times they used it with patients.

TPT Use by PDSA

Target Services Combined—TPT use is reported on a clinic-specific level as well as an aggregation across each PDSA cycle—see Figures 1 and 2. The bars in each figure represent the number of study patient encounters with TPT use, as well as the combined number of study and non-study patient encounters with TPT use. Use with study patients decreased over time. The research team expected this trend because study patients transitioned from pediatric to adult healthcare and recruitment concluded in March 2013 (Figure 1). TPT utilization was higher in PDSA 3 than the prior two PDSA cycles, following intensive targeted interventions by the research team. The most remarkable adoption of the TPT was observed following the dissemination of TPT 2.0 (PDSA 5).

Individual Clinics

Clinic A: Initially it was assumed that physicians, nurses, and social workers/case managers would all use the TPT in clinic A. However, through the first four PDSA cycles the physicians reported that time did not permit use of the tool; subsequently, the clinic staff decided to allocate the task to the social workers and case managers. Healthcare transition questions were regularly asked at many teen/young adult clinic visits and the TPT was used both before and after the visit. When the revised TPT was introduced, a physician became one of the main users.

Clinic B: The nurse practitioner was an early adopter of the TPT and the highest user in clinic B. While this clinic has the most physicians trained to use the TPT, there are two physicians who account for the majority of the remaining use. Insufficient time was cited as a barrier to use and providers in this clinic developed a solution in which they documented TPT activities within another area of the EMR platform.

Clinic C: Despite the section chief's strong support of the TPT, physicians did not adopt the TPT as anticipated. As a solution, the chief assigned two research nurses to integrate the TPT into transition planning for every study patient. In this clinic, TPT use did not generalize beyond the identified study patients. Patients in this clinic often transition to an adult health care clinic that is located in close physical proximity to the pediatric clinic. In PDSA 5, there was some uptake by the social worker in the adult clinic who was using the TPT to conduct ongoing knowledge and skills self-management training.

Clinic D: The section chief strongly promoted transition readiness although many of the clinic patients are dependent upon a caregiver. Although three physicians and one nurse were trained to use the TPT, The TPT has had no/little integration into their standard

operating procedures. Providers cited lack of time as the primary reason for not using the TPT during clinic visits.

Provider Survey: Satisfaction with the TPT—Twenty-one providers started PDSA 1. One provider left without completing any surveys. Four additional providers left their clinics during PDSA's 2, 3 or 4 and four new providers joined the project during PDSAs 3 and 4. A total of 18 of 20 (90%) providers completed provider survey #1 (end of PDSA 2), 17 of 20 providers (80%) completed provider survey #2 (end of PDSA 3), and 15 of 20 (75%) providers completed provider survey #3 (4 months into PDSA 5). The percent of providers who responded that they were “satisfied” or “very satisfied” with different aspects of TPT 1.0 (provider survey #1) and TPT 2.0 (provider survey #3) are reported in Table 2. User satisfaction increased across all items except the training provided prior to using the TPT and the technical assistance provided in troubleshooting TPT use because, in part, satisfaction with TPT 1.0 was already 90% for those two items. All providers reported TPT 2.0 was easier and faster to use, has a better flow sheet to follow patients and is more accessible as compared to TPT 1.0. Responses to user satisfaction questions were accompanied by open-ended TPT 2.0 comments recorded on the survey, such as “It is so easy to use,” “It is exactly what I needed,” “The transition button is terrific,” “Patients like it,” and “My patient said it makes them think about what they need to know.”

Provider Survey: Self-Assessed Transition Planning Activities—On provider survey #1, 57% of the providers, on average, reported that before they started using the TPT they “most of the time” or “always”

- Understood the needs of patients transitioning into adulthood;
- Offered the patient the opportunity to be interviewed without parents or guardians present;
- Ensured the patient is knowledgeable about their diagnosis and current treatments; helped the patient learn about self-management skills;
- Discussed with the patient eventually seeing an adult care provider; and
- Assisted in helping families plan for support if the patient will be unable to independently manage their care.

By PDSA 5, more than 80% of providers stated that they engaged in these transition planning activities with their patients. Provider comments during feedback sessions help interpret these findings. For example, asking the first TPT question “Tell me about your disease” helped providers realize what their patients did not know, which in turn, increased their understanding of the needs of their patients transitioning into adulthood.

Discussion

The results of this quality improvement project demonstrate that pediatric providers caring for youth in a large children's hospital are willing to use an EMR-based TPT provided it is easily accessible and simple to use and can be incorporated into routine patient care. The 88% of providers who used the TPT at least once exceeds the average 34% guideline

implementation rate reported in the literature (Mickan, Burls, & Glasziou, 2011). Moreover, self-assessment of HCT planning activities, such as ensuring the patient's knowledge about illness and talking to teens about eventually seeing an adult provider, increased across the five PDSA cycles, indicating that the process of being introduced to and using the TPT promoted a greater understanding of the complexity and need for transition planning processes overall. Anecdotal feedback suggests that prior to being exposed to the TPT the providers assumed the patients knew more about their illness than they actually did. The tool's structure prompted providers to be more patient-centered, directing their discussions at the patient's actual knowledge base. Talking to patients about eventually seeing an adult provider is one of the four core transition components identified by Lotstein et al. (2009).

The pediatric culture toward HCT changed over the course of developing and implementing the TPT. The fact that methods were being developed to assist with HCT planning (Paine et al., 2014; Reiss et al., 2005; van Staa et al., 2011), and provider input was sought through a continuous needs assessment process (provider surveys and feedback sessions and actual TPT use), furthered their interest and commitment (McAlearney, Hefner, Sieck, Rizer, & Huerta, 2014). This is illustrated by one representative provider comment: "HCT is much more complex than I thought it was, yet I am thinking about using [the TPT] with all my transition-aged patients now."

The TPT was developed as an interdisciplinary tool; accordingly, it was used by a broad spectrum of providers. Of the credentialed providers who employed the tool, nurses and social workers/case managers had the highest median use, followed by "other" providers and then physicians. TPT uptake was enhanced when a provider whose responsibilities included HCT planning with YSHCN and families was identified within each service. Physicians reported insufficient time as the greatest barrier to integrating the TPT into their daily workflow/practice. In response to this deterrent, the service chief in one clinic designated two research nurses (one of whom was a paid liaison on the project at 0.05% FTE) to use the TPT with every study patient. In another clinic without this resource, a social worker and case managers were enlisted to do so. In a third clinic, the nurse practitioner was the highest user. In the fourth clinic, the TPT did not become a priority for any provider. Barriers to health care providers' use of EMR systems have included navigating sequence of screens, time requirements, and confidentiality concerns (Likourezos et al., 2004), with nurses but not physicians reporting improved speed and efficiency using an EMR. Concerns that the TPT was too time-consuming for use were significantly reduced following the introduction of TPT 2.0. In fact, in one clinic mentioned above, the clinic chief became an active TPT user despite previously expressing concerns about being too busy to use it.

While the hands-on, personalized support for the TPT provided in PDSA 3 increased TPT use, it was not sustainable for system-wide adoption of "transition behavior." The most remarkable adoption of the TPT was observed following the dissemination of TPT 2.0 (PDSA 5), in which providers integrated the TPT into the typical clinic activities for all patients with minimal technical assistance from the research team. The improved TPT met the providers' requests for easier TPT access and a more intuitive process. Despite improved uptake during PDSA 5, some providers continued to cite insufficient time to integrate the TPT into clinic workflow as a barrier to optimum TPT use and many were using it with only

a fraction of transition age youth served. As users gained experience with the TPT, they began to perceive it as easy to use. Thus, concerns that the TPT is too time consuming may be attenuated as providers become more proficient at using it. It is also possible that institutional support to facilitate additional time during clinic appointments, staff availability, and financial backing (Clarizia et al., 2009; Scal, 2002; Woldorf, 2007) is needed.

This study is limited to four subspecialty services within a single hospital; thus findings may not generalize to other services or hospital systems. In addition, complete survey data were not collected on all TPT users, but it is the nature of academic medicine that providers come and go. Furthermore, providers may have been using questions from the TPT to guide transition planning but not documenting it in the EMR, resulting in an underestimation of the tool's impact. This study is also limited by relying on provider self-assessment of health care transition planning activities. Planning activities would need to be observed in clinic sessions in order to verify that they actually occurred. Finally, the impact of the TPT on actual patient transfer to adult health care is unknown, yet its use is the first step in promoting transition planning. It is expected that as the TPT is addressing patient safety, patient-centered care, timeliness, and equity, which are key components of the IOM's Quality of Care (Committee on Quality of Health Care in America & Institute of Medicine, 2001), there should be improved quality of care across health care transitions.

In summary, HCT is a new field and there are no evidence-based guidelines to promote successful transition from pediatric to adult-based care. HCT planning is a recommended step in improving HCT (Got Transition/Center for Health Care Transition, 2014) based on expert opinion. The development of a structured tool to facilitate transition planning is a first step in this process. The fact that a core set of providers were able to incorporate the TPT into their clinical practice serving patients with complex medical problems is encouraging. Improvement science methods may be used to promote and evaluate use of future versions of the TPT incorporating user-requested changes such as hard stops or best practice alerts (Abraham et al., 2014) and other potential facilitators, such as earning credit toward Maintenance of Certification, can incentivize pediatricians to adopt the TPT into their standard practice. Future studies will evaluate rollout of the TPT to more services within TCH and to additional children's hospitals. Furthermore, evaluating TPT use relative to patient-level readiness and to patient health outcomes will be critical for improving the preparation of young adults with special health care needs transitioning to adult-based care. The TPT piloted by four subspecialty services in this paper represents a core HCT infrastructure that could be used by all disease specific clinics or inpatient services in a children's hospital.

Acknowledgments

The authors wish to thank the clinic providers in The Baylor International Pediatric AIDS Initiative (BIPAI) and Retrovirology Clinic, Texas Children's Heart Center, Hematology Center, and Physical Medicine and Rehabilitation (PM&R) Clinics for volunteering to be trained to use the TPT, participating in feedback sessions and completing provider surveys; the TCH Epic support staff and data architects, particularly Kuo-Rei C. Mao and Weihong W. Li, for providing TPT use data in a timely manner; and Dr. Charles Macias for his consultation on the design of this quality improvement project.

Source of support: Supported by the Office of Title V & Family Health, Texas Department of State Health Services, using Title V Maternal and Child Health Services Block Grant Funds, grant no. 2014004647/0009819A;

the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant # D70MC23045, An Innovative Model for Facilitating Adult Services through Transition for Children & Youth with Special Health Care Needs for \$259,500. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. government.

References

- Abraham J, Kannampallil T, Patel VL. A systematic review of the literature on the evaluation of handoff tools: Implications for research and practice. *Journal of the American Medical Informatics Association*. 2014; 21:154–162. <http://dx.doi.org/10.1136/amiajnl-2012-001351>. [PubMed: 23703824]
- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002; 110:1304–1306. [PubMed: 12456949]
- Annunziato RA, Parkar S, Dugan CA, Barsade S, Arnon R, Miloh T, et al. Brief report: Deficits in health care management skills among adolescent and young adult liver transplant recipients transitioning to adult care settings. *Journal of Pediatric Psychology*. 2011; 36:155–159. <http://dx.doi.org/10.1093/jpepsy/jsp110>. [PubMed: 19995864]
- Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. *JAMA*. 2010; 303:1288–1294. <http://dx.doi.org/10.1001/jama.2010.378>. [PubMed: 20371788]
- Bryant R, Young A, Cesario S, Binder B. Transition of chronically ill youth to adult health care: Experience of youth with hemoglobinopathy. *Journal of Pediatric Health Care*. 2011; 25:275–283. <http://dx.doi.org/10.1016/j.pedhc.2010.02.006>. [PubMed: 21867855]
- Cabana MD, Rand CS, Becher OJ, Rubin HR. Reasons for pediatrician nonadherence to asthma guidelines. *Archives of Pediatrics and Adolescent Medicine*. 2001; 155:1057–1062. [PubMed: 11529809]
- Cabana MD, Rand CS, Powe NR, Wu AW, Wilson MH, Abboud PA, et al. Why don't physicians follow clinical practice guidelines? A framework for improvement. *JAMA*. 1999; 282:1458–1465. [PubMed: 10535437]
- Carlfjord S, Lindberg M, Bendtsen P, Nilsen P, Andersson A. Key factors influencing adoption of an innovation in primary health care: A qualitative study based on implementation theory. *BMC Family Practice*. 2010; 11:60. <http://dx.doi.org/10.1186/1471-2296-11-60>. [PubMed: 20731817]
- Clarizia NA, Chahal N, Manlhiot C, Kilburn J, Redington AN, McCrindle BW. Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider. *Canadian Journal of Cardiology*. 2009; 25:e317–e322. [PubMed: 19746251]
- Committee on Quality of Health Care in America, & Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. National Academies Press; 2001.
- Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011; 128:182–200. <http://dx.doi.org/10.1542/peds.2011-0969>. [PubMed: 21708806]
- de Veer A, Fleuren M, Bekkema N, Francke A. Successful implementation of new technologies in nursing care: A questionnaire survey of nurse-users. *BMC Medical Informatics and Decision Making*. 2011; 11:1–12. <http://dx.doi.org/10.1186/1472-6947-11-67>. [PubMed: 21211015]
- Deming, WE. The new economics for industry, education, government. Cambridge, MA: MIT Press; 1994.
- Doerr M, Edelman E, Gabitzsch E, Eng C, Teng K. Formative evaluation of clinician experience with integrating family history-based clinical decision support into clinical practice. *Journal of Personality Medicine*. 2014; 4:115–136. <http://dx.doi.org/10.3390/jpm4020115>.
- Eslami S, de Keizer NF, Abu-Hanna A. The impact of computerized physician medication order entry in hospitalized patients—A systematic review. *International Journal of Medical Informatics*. 2008; 77:365–376. <http://dx.doi.org/10.1016/j.ijmedinf.2007.10.001>. [PubMed: 18023611]

- Family Voices. Family-Centered Care Self-Assessment Tool: Provider Tool. 2008. from http://www.fv-ncfpp.org/files/4113/0626/9064/fcca_ProviderTool.pdf
- Foy R, MacLennan G, Grimshaw J, Penney G, Campbell M, Grol R. Attributes of clinical recommendations that influence change in practice following audit and feedback. *Journal of Clinical Epidemiology*. 2002; 55:717–722. [PubMed: 12160920]
- Goodman DM, Hall M, Levin A, Watson RS, Williams RG, Shah SS, et al. Adults with chronic health conditions originating in childhood: Inpatient experience in children's hospitals. *Pediatrics*. 2011; 128:5–13. <http://dx.doi.org/10.1542/peds.2010-2037>. [PubMed: 21708805]
- Got Transition/Center for Health Care Transition. Got transition. 2014. from <http://www.gottransition.org/>
- Hankins JS, Osarogiagbon R, Adams-Graves P, McHugh L, Steele V, Smeltzer MP, et al. A transition pilot program for adolescents with sickle cell disease. *Journal of Pediatric Health Care*. 2012; 26:e45–e49. <http://dx.doi.org/10.1016/j.pedhc.2012.06.004>. [PubMed: 22819193]
- Hergenroeder, AC.; Wiemann, CM.; Bowman, VF.; Flanagan, S. Impact of an electronic medical record-based transition planning tool on health care transition planning and patient/family perception of this planning for children & youth with special health care needs. Paper presented at the Pediatric Academic Societies/Society for Pediatric Research; Boston, MA. 2012.
- Hersh AO, Pang S, Curran ML, Milojevic DS, von Scheven E. The challenges of transferring chronic illness patients to adult care: Reflections from pediatric and adult rheumatology at a US academic center. *Pediatric Rheumatology Online Journal*. 2009; 7:13. <http://dx.doi.org/10.1186/1546-0096-7-13>. [PubMed: 19505332]
- Howard GS, Ralph KM, Gulanick NA, Maxwell SE, Nance DW, Gerber SK. Internal invalidity in pretest-posttest self-report evaluations and a re-evaluation of retrospective pretests. *Applied Psychological Measurement*. 1979; 3:1–23. <http://dx.doi.org/10.1177/014662167900300101>.
- Kelly AM, Kratz B, Bielski M, Rinehart PM. Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics*. 2002; 110:1322–1327. [PubMed: 12456952]
- Khanna SK, Cheyney M, Engle M. Cultural competency in health care: Evaluating the outcomes of a cultural competency training among health care professionals. *Journal of the National Medical Association*. 2009; 101:886–892. [PubMed: 19806845]
- Klein JD, Sesselberg TS, Johnson MS, O'Connor KG, Cook S, Coon M, et al. Adoption of body mass index guidelines for screening and counseling in pediatric practice. *Pediatrics*. 2010; 125:265–272. <http://dx.doi.org/10.1542/peds.2008-2985>. [PubMed: 20083518]
- Laird-Fick HS, Solomon D, Jodoin C, Dwamena FC, Alexander K, Rawsthorne L, et al. Training residents and nurses to work as a patient-centered care team on a medical ward. *Patient Education and Counseling*. 2011; 84:90–97. <http://dx.doi.org/10.1016/j.pec.2010.05.018>. [PubMed: 20554421]
- Likourezos A, Chalfin DB, Murphy DG, Sommer B, Darcy K, Davidson SJ. Physician and nurse satisfaction with an electronic medical record system. *Journal of Emergency Medicine*. 2004; 27:419–424. <http://dx.doi.org/10.1016/j.jemermed.2004.03.019>. [PubMed: 15498630]
- Lotstein DS, Ghandour R, Cash A, McGuire E, Strickland B, Newacheck P. Planning for health care transitions: Results from the 2005–2006 National Survey of Children With Special Health Care Needs. *Pediatrics*. 2009; 123:e145–e152. <http://dx.doi.org/10.1542/peds.2008-1298>. [PubMed: 19117836]
- Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: Results from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2005; 115:1562–1568. <http://dx.doi.org/10.1542/peds.2004-1262>. [PubMed: 15930217]
- Ludwick DA, Doucette J. Adopting electronic medical records in primary care: Lessons learned from health information systems implementation experience in seven countries. *International Journal of Medical Informatics*. 2009; 78:22–31. <http://dx.doi.org/10.1016/j.ijmedinf.2008.06.005>. [PubMed: 18644745]
- McAlearney AS, Hefner JL, Sieck C, Rizer M, Huerta TR. Evidence-based management of ambulatory electronic health record system implementation: An assessment of conceptual support and qualitative evidence. *International Journal of Medical Informatics*. 2014; 83:484–494. <http://dx.doi.org/10.1016/j.ijmedinf.2014.04.002>. [PubMed: 24862893]

- McLaughlin S, Bowering N, Crosby B, Neukirch J, Gollub E, Garneau D. Health care transition for adolescents with special health care needs: A report on the development and use of a clinical transition service. *Rhode Island Medical Journal*. 2013; 96:25–27. [PubMed: 23641448]
- McManus, MA.; Fox, H.; O'Connor, K.; Chapman, T.; MacKinnon, J. Pediatric perspectives and practices on transitioning adolescents with special needs to adult health care. Washington DC: National Alliance to Advance Adolescent Health; 2008.
- McManus MA, Pollack LR, Cooley WC, McAllister JW, Lotstein D, Strickland B, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013; 131:1090–1097. <http://dx.doi.org/10.1542/peds.2012-3050>. [PubMed: 23669518]
- Mickan S, Burls A, Glasziou P. Patterns of 'leakage' in the utilisation of clinical guidelines: A systematic review. *Postgraduate Medical Journal*. 2011; 87:670–679. <http://dx.doi.org/10.1136/pgmj.2010.116012>. [PubMed: 21715571]
- Monforto K, Figueroa-Altmann A, Stevens C, Thiele K, Ely E. Time changes for scheduled nursing assessments: Impact on clinical decisions and patient discharge. *Journal of Pediatric Nursing*. 2012; 27:26–33. <http://dx.doi.org/10.1016/j.pedn.2010.11.002>. [PubMed: 22222103]
- National Association of Pediatric Nurse Practitioners. NAPNAP position statement on age parameters for pediatric nurse practitioner practice. *Journal of Pediatric Health Care*. 2014; 28:A15–A16. <http://dx.doi.org/10.1016/j.pedhc.2014.03.001>.
- National Committee for Quality Assurance. Standards and guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2011. Washington DC: 2011.
- Ogrinc G, Mooney SE, Estrada C, Foster T, Goldmann D, Hall LW, et al. The SQUIRE (Standards for Quality Improvement Reporting Excellence) guidelines for quality improvement reporting: Explanation and elaboration. *Quality & Safety in Health Care*. 2008; 17:i13–i32. <http://dx.doi.org/10.1136/qshc.2008.029058>. [PubMed: 18836062]
- Okumura MJ, Hersh AO, Hilton JF, Lotstein DS. Change in health status and access to care in young adults with special health care needs: Results from the 2007 national survey of adult transition and health. *Journal of Adolescent Health*. 2013; 52:413–418. <http://dx.doi.org/10.1016/j.jadohealth.2012.08.005>. [PubMed: 23298998]
- Paine CW, Stollon NB, Lucas MS, Brumley LD, Poole ES, Peyton T, et al. Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the perspectives of providers. *Inflammatory Bowel Diseases*. 2014; 20:2083–2091. <http://dx.doi.org/10.1097/mib.000000000000136>. [PubMed: 25137417]
- Peters A, Laffel L. Diabetes care for emerging adults: Recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). *Diabetes Care*. 2011; 34:2477–2485. <http://dx.doi.org/10.2337/dc11-1723>. [PubMed: 22025785]
- Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell disease. *Blood*. 2010; 115:3447–3452. <http://dx.doi.org/10.1182/blood-2009-07-233700>. [PubMed: 20194891]
- Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics*. 2005; 115:112–120. <http://dx.doi.org/10.1542/peds.2004-1321>. [PubMed: 15629990]
- Rose AF, Schnipper JL, Park ER, Poon EG, Li Q, Middleton B. Using qualitative studies to improve the usability of an EMR. *Journal of Biomedical Informatics*. 2005; 38:51–60. <http://dx.doi.org/10.1016/j.jbi.2004.11.006>. [PubMed: 15694885]
- Sawicki GS, Whitworth R, Gunn L, Butterfield R, Lukens-Bull K, Wood D. Receipt of health care transition counseling in the national survey of adult transition and health. *Pediatrics*. 2011; 128:e521–e529. <http://dx.doi.org/10.1542/peds.2010-3017>. [PubMed: 21824879]
- Scal P. Transition for youth with chronic conditions: Primary care physicians' approaches. *Pediatrics*. 2002; 110:1315–1321. [PubMed: 12456951]

- Scal P, Davern M, Ireland M, Park K. Transition to adulthood: Delays and unmet needs among adolescents and young adults with asthma. *The Journal of Pediatrics*. 2008; 152:471–475.e471. <http://dx.doi.org/10.1016/j.jpeds.2007.10.004>. [PubMed: 18346498]
- Shaw KL, Southwood TR, McDonagh JE. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford)*. 2004; 43:770–778. <http://dx.doi.org/10.1093/rheumatology/keh175>. [PubMed: 15039498]
- Shiffman RN, Freudigman M, Brandt CA, Liaw Y, Navedo DD. A guideline implementation system using handheld computers for office management of asthma: Effects on adherence and patient outcomes. *Pediatrics*. 2000; 105:767–773. [PubMed: 10742318]
- Sittig DF, Kuperman GJ, Fiskio J. Evaluating physician satisfaction regarding user interactions with an electronic medical record system. *Proc AMIA Symp*. 1999:400–404. [PubMed: 10566389]
- Skeff KM, Stratos GA, Bergen MR. Evaluation of a medical faculty development program: A comparison of traditional pre/post and retrospective pre/post self-assessment ratings. *Evaluation & the Health Professions*. 1992; 15:350–366. <http://dx.doi.org/10.1177/016327879201500307>.
- Telfair J, Alexander LR, Loosier PS, Alleman-Velez PL, Simmons J. Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *Journal of Health Care for the Poor and Underserved*. 2004; 15:443–461. [PubMed: 15453180]
- Texas Parent to Parent. Texas Parent to Parent. 2015. from <http://txp2p.org/>
- van Staa AL, Jedeloo S, van Meeteren J, Latour JM. Crossing the transition chasm: Experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development*. 2011; 37:821–832. <http://dx.doi.org/10.1111/j.1365-2214.2011.01261.x>.
- White P, Kenton K. Use of electronic medical record-based tools to improve compliance with cervical cancer screening guidelines: Effect of an educational intervention on physicians' practice patterns. *Journal of Lower Genital Tract Disease*. 2013; 17:175–181. <http://dx.doi.org/10.1097/LGT.0b013e3182607137>. [PubMed: 23343700]
- Woldorf JW. Transitioning adolescents with special healthcare needs: Potential barriers and ethical conflicts. *Journal for Specialists in Pediatric Nursing*. 2007; 12:53–55. <http://dx.doi.org/10.1111/j.1744-6155.2007.00089.x>. [PubMed: 17233668]
- Woodward JF, Swigonski NL, Ciccarelli MR. Assessing the health, functional characteristics, and health needs of youth attending a noncategorical transition support program. *Journal of Adolescent Health*. 2012; 51:272–278. <http://dx.doi.org/10.1016/j.jadohealth.2011.12.016>. [PubMed: 22921138]
- Yank V, Laurent D, Plant K, Lorig K. Web-based self-management support training for health professionals: A pilot study. *Patient Education and Counseling*. 2013; 90:29–37. <http://dx.doi.org/10.1016/j.pec.2012.09.003>. [PubMed: 23031610]

Figure 1.
 Transition planning tool (TPT) utilization across all four study clinics during plan–do–study–act (PDSA) cycles 1–5.

Figure 2. Transition planning tool (TPT) utilization by study clinic during plan–do–study–act (PDSA) cycles 1–5.

Table 1**Providers characteristics**

Characteristic	<i>N</i> = 25
Gender	
Female	22
Male	3
Subspecialty	
Retrovirology	7
Hematology	10
Cardiology	4
PM&R	4
Discipline	
Physician	10
Nurse ^{<i>a</i>}	8
Social worker/case manager	4
Other ^{<i>b</i>}	3
Graduation year	
1970–1979	3
1980–1989	2
1990–1999	5
2000–2010	13
2011–2013	2

^{*a*}Includes nurse practitioners, research nurses and LVN.

^{*b*}Other: 1 child life specialist and 2 research coordinators.

Table 2
Provider survey: percent who reported being satisfied with the TPT ^a

	TPT 1.0 ^b (n = 18)	TPT 2.0 ^c (n = 15)
<i>In reference to the TPT, how satisfied are you with...</i>		
The ease of using the TPT?	47%	80%
The flow between titles, topics and teaching points?	50%	80%
The TPT summary page (review flow sheet) helping you to follow a patient through the transition process?	59%	87%
The time it takes to utilize the TPT in clinic?	37%	67%
The training you were given prior to using the TPT?	94%	80%
Technical assistance or troubleshooting in using the TPT?	90%	87%
The accessibility of the TPT?	61%	80%

^a Items developed using instruments from published studies (Rose et al., 2005; Sittig et al., 1999).

^b Providers who reported being "satisfied" or "very satisfied" on provider survey #1.

^c Providers who reported being "satisfied" or "very satisfied" on provider survey #2.

Table 3
Provider survey: transition planning activities

Looking back, prior to starting to use the TPT, how often did you... (and) Since starting to use the TPT, how often do you...
Help the patient learn about self-management of their health? ^a
Ensure the patient is knowledgeable about their diagnosis and current treatments? ^a
Confirm that the patient can discuss their diagnosis with an adult care provider? ^a
Help the family and patient develop a formal health care transition plan? ^a
Talk to families and patients about their vision for the future (education, dreams, meaningful work, social relationships, and financials)? ^a
Assist in helping families plan for support if the patient will be unable to independently manage their care? ^a
Understand the needs of patients transitioning into adulthood? ^b
Discuss with the patient eventually seeing an adult care physician or other adult health care provider? ^b
Offer the patient the opportunity to be interviewed without parents or guardians present? ^b

^aAdapted from the Family-Centered Care Self-Assessment Tool (Family Voices, 2008).

^bDeveloped for this study based on discussions with content experts and reviewing literature (Lotstein et al., 2005, 2009; Sawicki et al., 2011).

Table 4
TPT use for each of the four study clinics

	Clinic A	Clinic B	Clinic C	Clinic D
Number of trained users (<i>N</i> = 25)	7	10	4	4
Number of trained users who used the TPT at least once	7	8	4	3
Encounters with use ^a				
Total number	133	102	59	9
Mean $\pm$ SD	19.0 $\pm$ 27.2	10.5 $\pm$ 13.0	14.8 $\pm$ 7.2	2.25 $\pm$ 2.2
Median	10	4.5	14	2
Range	2-79	0-37	7-24	0-5
Total number of patients with use (study and non-study)	65	77	32	8
Number of study patients with use	24	19	28	6
Total number of study subjects recruited	28	24	36	21
Proportion of study patients with TPT use	85.7%	79.1%	77.8%	28.6%
Number of non-study patients with use	41	58	4	2

^aThe number of encounters with use is greater than the number of patients with use as the TPT is expected be used on more than one occasion with each patient.