

## ***Texas Children's Hospital Health Care Transition Planning Tool***

Location: Texas  
 Date Submitted: 9/2015  
 Category: **Best Practice**

### **TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED**

- #10: Percent of adolescents with a preventive services visit in the last year
- #11: Percent of children with and without special health care needs having a medical home
- #12: Percent of children with and without special health care needs who received services necessary to make transitions to adult health care
- #15: Percent of children 0 through 17 years who are adequately insured

### **BACKGROUND**

Ninety percent of adolescents with special health care needs will survive into adulthood; yet there are increased morbidity and mortality rates for young adults as they transition into adult-based care. Adolescents/young adults with special health care needs (AYASHCN) are not prepared for health care transition and there is no evidence, based on a national sample of parent of children and youth with special health care needs, that health care transition planning improved between 2005 and 2010.

Despite universally agreeing that it is an important gap in caring for these youth, pediatric health care providers are not prepared to assist in transition readiness for AYASHCN and their families. Evidence-based methods to promote the successful transition of AYASHCN are needed. Additionally, there is a need to improve this transition to adult-based by developing transition planning tools that providers can use to facilitate transition planning for youth and their families.

The Transition Planning Tool focuses on closing the gap primarily serving Adolescents and Children/Youth with Special Health Care Needs. This tool is embedded in an electronic medical record and can be used by providers from any discipline to promote improved transition knowledge and skills on the part of adolescents with chronic illness and disability.

### **PROGRAM GOALS & OBJECTIVES**

The overall goal of the program is to improve transition readiness among adolescents/young adults with special health care needs (AYASHNC) through provider use of an electronic medical record (EMR)-based health care transition

(HCT) transition planning tool (TPT), and in so doing, reduce the morbidity and mortality associated with transitioning from pediatric to adult-based care.

The objectives of the tool are:

- To build an EMR-based TPT to facilitate health care transition planning
- To employ quality improvement methods to promote provider use of the TPT
- To increase the number of AYASHNC who successfully transition to (attend their first adult provider appointment) and engage in adult-based care (attend  $\geq 2$  appointments)
- To increase the number of AYASHCN who arrive at their adult appointment with a portable medical summary.

### **TARGET POPULATION SERVED**

AYASHCN ages 14-25 years under medical care who are planning to transition from pediatric to adult-based health care

### **PROGRAM ACTIVITIES**

Developing, implementing and evaluating a health care TPT, created with input from Family and Youth Advisory Boards and both pediatric and adult health care providers that directly or indirectly addresses five of the six core transition support indicators set forth by GOT TRANSITION! The TPT is an assessment and education tool designed to facilitate health care transition planning during a clinic visit in order to prepare AYASCHCN and their families to transition to adult-based care.

Implementation included training providers to use the tool, promoting and troubleshooting its use, and expanding its use in multiple hospital clinics as well as inpatient and community-based practice settings.

## EVALUATION DATA

Over the past 6 years, grants from the Texas Department of State & Health Services (DSHS) (2009-2015) and Health Resources and Services Administration (HRSA) Children with Special Health Care Needs (CSHCN) program (2011-2014) have funded projects to promote and evaluate TPT use in four specialty clinics (Hematology, Retrovirology, Congenital Cardiac Disease and Physical Medicine and Rehabilitation). Funding permitted expanding TPT use to the remaining TCH clinical enterprise and enabled outcomes as youth transfer out of pediatric and into adult care to be evaluated. Later in this report, these four clinics are randomly referred to as Clinic A, B, C, and D for the sake of anonymity.

- **Structure** was evaluated by creating the TPT and verifying that it was available to providers throughout the TCH enterprise via the Epic EMR, and making modifications based on user feedback and patient outcomes.

- **Process** was evaluated by noting which providers attended user and individual service meetings; the number of providers who were trained to use the TPT and who actually used it; the number of patient encounters with TPT use and the number of “successfully accomplished” questions per patient; the number of outpatient services and community-based practices that used the TPT; provider satisfaction with TPT use; and improvements to the TPT over time.

- **Outcomes** included the number of transitioning youth who met the “core transition outcome”; the number of youth who transferred out of pediatric care who attended their first adult appointment (transitioned); the number of youth who transferred out of pediatric care who attended at least two adult appointments (engaged); and the number of transitioned youth who brought their portable medical summary to their adult doctor's appointment.

### **Methods to promote TPT use and evaluate structure, process and outcomes**

Methods used to promote TPT use and evaluate structure, process and outcomes were described in a recently published quality improvement project and reviewed. These methods included Plan, Do, Study, Act (PDSA) cycles, incorporating weekly data reports on TPT use, weekly contact with the services using the TPT through email and support in clinic, regular meetings (every 6-12 weeks) with TPT users to obtain feedback, and interviewing youth and parents about their experiences during transition planning

and after transition to adult care. Five PDSA cycles, used to promote and evaluate the main process measure, TPT utilization, were carried out over a 35-month period:

- **PDSA 1** (March 2012-July 2012): Baseline phase that studied passive TPT use prior to formal study commencement.
- **PDSA 2** (August 2012-March 2013): Study providers (n=24) trained in TPT 1.0 use.
- **PDSA 3** (April 2013-November 2013): Increased frequency of study provider meetings to problem solve TPT usage barriers and increased technical assistance (there were over 10 user meetings)
- **PDSA 4** (December 2013 – April 2014): TPT 2.0 was built into the EMR and made available to study providers (n=20), but promotion of its use was limited. This phase served as the baseline for TPT 2.0.
- **PDSA 5** (May 2014 – December 2014): TPT 2.0 training beyond existing users and services, as well as Epic Educators and Care Coordinators.

A subset of TCH patients treated by the four subspecialty services was enrolled in a study on HCT planning and 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 (PDSA cycles 1 & 2). Of the 143 patients approached as they attended a scheduled clinic appointment, 109 agreed to participate – with 28 patients from Clinic A, 24 from Clinic B, 36 from Clinic C, and 21 from Clinic D.

### **Process**

Utilization of the TPT was the primary process measure. The investigative team reviewed weekly Epic-generated TPT use reports across the four subspecialty clinics. This yielded the number of encounters with use (which includes face-to-face clinic visits and phone encounters) among age eligible study and non-study patients 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.

Provider Satisfaction and Self-reported Transition Planning Activities were secondary process measures assessed by a survey administered in three different phases of the project. Providers indicated their degree of satisfaction with the ease of using the TPT; the flow between titles, topics and teaching points; the TPT summary page and the time it takes to utilize the TPT in clinic. Barriers to use and suggestions for improvement were reported. Each survey also asked providers to evaluate how often they engaged in a set of



transition planning activities before and after starting to use the TPT. Sample items include: Help the patient learn about self-management of their health? Ensure the patient is knowledgeable about their diagnosis and current treatments?

### Outcomes

The TCH patients enrolled in the study completed baseline and follow-up questionnaires (about 12 months later) to assess key elements in successful transition planning for AYASHCN. These included questions assessing the core transition outcome: having discussions with a health care provider about future adult health care needs, finding an adult provider and securing health insurance, and encouraging young adults to take more responsibility for their care. Baseline and 12-month questionnaires also assessed the patients' and caregivers' perception of the transition process. Patients completed up to two post-transition questionnaires that asked them if they currently have an adult-based doctor they see for their diagnosis and whether they attended a first appointment brought their Portable Medical Summary to that appointment. Patients were also asked if they have seen their adult provider more than once. Methods to maintain contact with AYASHCN after leaving pediatric care included collecting detailed contact information, providing gift cards for completing each questionnaire to compensate them for their time, and communicating by phone and through email, text messaging and regular mail.

## PROGRAM OUTCOMES

### Structure

The TPT was made available to four services in 2012. This expanded to 21 services by 2015 and is currently available for use across the TCH enterprise, including all outpatient services, inpatient services, and community-based primary care practices. Improvements to the TPT as it moved from version 1.0 to version 2.0 included being able to access the TPT by one click on the favorites menu in the patient's chart; having an overall "report" appear in the flow sheet showing progress on transition planning; and linking supporting documents directly to the core questions in the TPT. Provider survey data identified that the majority (>90%) of study providers were satisfied with TPT 2.0; all reported that TPT 2.0, as compared to TPT 1.0, was easier and faster to use, has a better flow sheet to follow patients and is more accessible. There was broad uptake in all study and non-study services with relatively little technical assistance, in contrast to TPT 1.0, which required significant research team guidance.

Since December 2013, providers have shared feedback regarding desired improvements in the third iteration of the TPT (TPT 3.0). These changes are in discussion with TCH Epic experts and a PDSA 6 cycle is planned when version

3.0 becomes available. Some of the updates will involve automatically including the name of the provider and the clinic in the TPT when use occurs; and automatically incorporating the TPT entries for each day into the clinic notes.

### Process

In the focused study of the four specialty services, 25 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±17.5). TPT use rates varied by clinic, which we identify here. 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).

There are notable distributions among providers according to their discipline: four case managers/social workers had 114 encounters with use (median=15, range=5-79); 102 uses by six nurses (median=15.5, range=3-37), 60 uses by nine physicians (median=5.0, range=1-18), and 30 uses by three others (median=12.0, range=2-16). 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 was reported aggregated across the four clinics in each PDSA cycle and included use with both study and non-study patients. Overall, TPT use increased steadily from 4.5 uses per month to 15 uses per month. Use with study patients decreased over time as they transitioned from pediatric to adult healthcare and recruitment stopped in March 2013. 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).

During the study period, the TPT was made available to the entire TCH clinical enterprise and spread to 21 clinical services at TCH.

### *Provider Survey: Satisfaction with the TPT*

By PDSA 5, user satisfaction with the TPT averaged 80% or greater. 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. 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," also provided evidence of provider satisfaction.

#### *Provider Survey: Self-Assessed Transition Planning Activities*

By PDSA 5, more than 80% of providers stated that they engaged in transition planning activities with their patients. Providers commented that asking the first TPT question "Tell me about your disease" helped them realize what their patients did not know, which in turn, increased their understanding of the needs of their patients transitioning into adulthood. Thus, the TPT facilitates transition planning conversations. In the community-based primary care setting, the TPT provides a structure from which to conduct interdisciplinary huddles prior seeing patients.

#### **Outcomes**

An important outcome was to assess the impact of the use of the TPT on the "core transition outcome" (National Survey – CSHCN) and completion of the participants' first adult appointment. Participants (ages 16-25 years) recruited from the three specialty clinics between February 2012 and March 2013 completed a baseline questionnaire (n=88) and a follow-up questionnaire about 12 months later (n=74). All participants were followed for at least two years to determine their adult appointment completion status. Of the 88 participants, 44 have transferred out of TCH and their adult provider status is known: 35/44 (79.5%) transitioned to an adult provider and 9/44 (20.5%) have not. An additional 9/88 (10.2%) transferred out of pediatric care and it is unknown whether they have seen an adult provider; 25/88 (28.4%) were still being seen at TCH; 7/88 (8%) have not been seen at TCH during this period, yet we do not know if they have transferred to adult-based care; and 3/88 (3.4%) were deceased.

Of the 88 participants, the mean number of patient encounters with TPT use in those with at least one use (65/88, 73.9%) was  $1.9 \pm 0.9$  times over 12 months. The mean number of successfully accomplished questions in those with at least one SA (59/88, 67.0%) was  $4.9 \pm 2.7$ . The number of TPT SA questions, but not the number of TPT uses, was related to the participant's perception of the core transition outcome being met ( $p=0.035$ ). Those who met the core transition outcome were more likely to visit an adult provider (88.9%) compared to those who did not meet the core transition outcome (73.1%) ( $p=0.186$ ).

#### **PROGRAM COST**

The TPT is currently available as an Epic Clinical Program free of charge to systems that use the Epic electronic medical record. Approximately .50FTE is needed to provide technical assistance in training providers in multiple clinics to

use the TPT, help troubleshoot tool use and update the TPT handouts.

#### **ASSETS & CHALLENGES**

##### Assets:

The TPT is currently available as an Epic Clinical Program. However, the basic TPT principles can be applied to either a paper-based medical record or electronic medical record system. 81 handouts/work sheets in English and 71 handouts in Spanish are linked to the core questions to help improve knowledge and skills related to disease self-management. These are available upon request. A survey that assesses provider satisfaction with the TPT and changes in self-reported transition planning activities as a result of TPT use is also available upon request.

##### Overcoming Challenges:

Lessons learned in the process of building a hospital-wide healthcare transition (HCT) planning infrastructure that could help patients transition from pediatric to adult-based care regardless of disease/disability were identified and described in a recently published peer-review paper (Hergenroeder et al., 2015), and are summarized here. A solid foundation on which to build a hospital-based HCT planning program includes: focusing on structure and processes needed to facilitate medical transition; conducting a baseline assessment of current transition policy/practice; building an understanding of the complexity and necessity of transition planning; identifying advocates for transition planning and adult providers who will accept youth with chronic medical conditions; and establishing methods to evaluate transition program building activities.

#### **FUTURE STEPS**

The HCT TPT will be sustained through its proliferation throughout the Texas Children's Hospital (TCH) Integrated Delivery System, including the TCH Health Plan, which covers 300,000 lives and the fact that it has been adopted as an Epic Clinical Program available nationwide. Next steps include piloting an upgraded TPT (version 3.0), promoting access to the portable medical summary through the web-based patient portal, and evaluating transition outcomes.

#### **COLLABORATIONS**

Peer/stakeholder input and identifying and incorporating lessons learned have been integral parts of the process of developing, implementing, modifying, and evaluating the TPT. Below are some highlights of these experiences:

- A needs assessment was conducted with TCH service chiefs in 2004. Sixty-nine percent of the respondents (9/13) indicated that their service routinely transitioned patients to a physician who cared for adult patients; 8% (1/13) had an



unwritten protocol for transition; 46% (6/13) identified physicians to whom they refer their patients; and 83% (10/12) wanted help with transition planning. Committee members met with the hospital's Family Advisory Board, consisting of parents of YSHCN cared for at the hospital, and the Youth Advisory Board, consisting of YSHCN being treated at the hospital, about their knowledge of the hospital's HCT activities and their HCT needs.

- The first version of the TPT was developed over 12 months, with input from the hospital's Family and Youth Advisory Boards and with feedback from both pediatric and adult-based providers.

- TPT user meetings and individual service provider meetings, held at least quarterly for the past seven years, have provided a continuous feedback loop on barriers to using the tool as well as a venue to share successful strategies to overcome them.

- Providers have completed four surveys every 6-8 months so that provider satisfaction with the TPT, perceived changes in transition provider planning activities since being introduced to the TPT, barriers to use, and suggestions for improvement could be assessed at timely intervals. Stakeholder input led directly to the development of an improved, streamlined version of the TPT (2.0) that is easier to locate in the EMR and use. A third version (TPT3.0) is planned for late 2015 or early 2016.

The implementation of any HCT program will depend on creating a culture that expects successful HCT to be the culmination of successful pediatric care. Hospital support (resources, staff training and an expanded infrastructure into which the program can fit) is necessary for a sustainable HCT planning program.

## PEER REVIEW & REPLICATION

1. Wiemann CM, Hergenroeder AC, Bartley KA, Sanchez-Fournier BE, Hilliard ME, Warren LJ, and Graham SC. Integrating an EMR-based Transition Planning Tool for CYSHCN at a Children's Hospital: A Quality Improvement Project to Increase Provider Use and Satisfaction. *J Pediatr Nurs.* 2015 Jul 21. pii: S0882-5963(15)00211-0. doi: 10.1016/j.pedn.2015.05.024. [Epub ahead of print] PMID: 26209173.

2. Hergenroeder AC, Wiemann CM, Bowman VF. Lessons learned in building a hospital-wide transition program from pediatric to adult-based health care for youth with special health care needs (YSHCN). *Int J Adolesc Med Health.* 2015 Sep 11. pii: /j/ijamh.ahead-of-print/ijamh-2015-0048/ijamh-2015-0048.xml. doi: 10.1515/ijamh-2015-0048.

TPT 2.0 was initially piloted in December 2013 in five services. Since then it has become a core structural element in TCH's overall HCT efforts. The TPT has been used by a total of 21 TCH services/clinics, yielding 1236 TPT encounters with 839 patients by 146 providers. TPT use has also expanded from outpatient main campus use to use across the entire TCH enterprise, which includes inpatient community-based primary care clinics. Provider disciplines that used the TPT have included physicians, psychiatrists, nurse practitioners, psychologists, registered nurses, social workers, dietitians, case managers, fellows, and residents.

The TPT is also available as an Epic Clinical Program. As of April 2014, the Transition Planning Tool Epic Clinical program has been downloaded 120 times by 74 healthcare systems across the nation.

## RESOURCES PROVIDED

<https://galaxy.epic.com/?#Browse/page=1!68!600!1733006>

