Transitioning to a Better Future: Building a Pediatric Transition Tool for Sickle Cell Disease

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Abstract

Adaption of an electronic medical record-based transitioning planning tool (TPT) to standardize and guide transition of pediatric patients to adult care for sickle cell disease patients age 12-21 was introduced in the hematology oncology clinic of a large academic children's hospital. Interventions to promote and increase provider engagement and utilization were implemented in three plan-do-study-act cycles. In total three of three (100%) of providers involved in the quality improvement efforts in the clinic used the transition tool during 12 patient encounters. Use was isolated to these three providers based on the narrow scope of the initial piloting project and the population size. Use of the tool was highest with greater appointment time spent on addressing transition. Provider satisfaction with the tool and self-reported transition activities showed a modest increase from pre-implementation to post-implementation.

Keywords: Electronic medical record; transition planning; PDSA; Quality improvement; Sickle cell disease; Hematology oncology

Problem Description

Sickle Cell Disease (SCD) is a chronic autosomal recessive disease that is known for vaso-occlusion of organs by dysmorphic red blood cells (Varty & Popejoy, 2020). Sickle cell leads to acute injury, and end organ and tissue damage occurs as a result. This damage can be lasting and lead to chronic complications of the disease (Campbell et al., 2020; Song et al., 2019). Over 100,0000 individuals in the United States (US) are affected by sickle cell disease, and most identify as Black or of African ancestry (National Heart, Lung, and Blood Institute [NHLBI], 2018). Approximately one in three Black or African American babies is born with sickle cell trait, and 1 in every 365 is born with sickle cell disease (NHLBI, 2018). Over 2,000 children are born each year in the US with the disease (Sobota et al., 2011). Many people of other backgrounds also suffer from sickle cell disease including those of Hispanic, southern European, Middle Eastern, Asian Indian, and Latin American origins (NHLBI, 2018). Pediatric SCD patients who enter into adult healthcare have increased utilization of acute care services (Brandow et al., 2020). In the first two years after transition, patients have an increased mortality, higher rates of rehospitalization, and receive less preventative care. Many of these challenges are associated with poor transition from pediatric to adult care (Brandow et al., 2020; Lanzkron et al., 2018; Varty & Popejoy, 2020).

Transition is the intentional and directed process of promoting and developing the skills that a pediatric patient needs to successfully transfer to adult care. This includes but is not limited to the development of the necessary skills and knowledge to navigate one's disease process, and readiness to transfer to an adult provider by the set age for transfer of care (Lanzkron et al., 2018). According to GotTransition (2021), transition should be introduced by 12 years of age, and by 21, transfer of care from pediatric to adult care should be accomplished

(GotTransition/Center for Healthcare Transition, 2014). In this day and age many patients with what used to be fatal chronic diseases are surviving into adulthood, and sickle cell patients are among them (Lanzkron et al., 2018). There was a time when sickle cell patients did not make it past pediatric specialty care, but now many are living well into their 40's, 50's, and even 60's (Bryant et al., 2016; Lanzkron et al., 2018). The focus of sickle cell management has always been in the pediatric population, and as the number of adult patients with sickle cell grows, it is becoming obvious that care gaps exist in transition and specialty adult care for this unique population of patients (Varty & Popejoy, 2020). Routine transfer of SCD patients to adult specialty care happens only 60% of the time, and lack of an adult provider with interest or specialization in SCD is a barrier (Bryant et al., 2016; Travis et al., 2020, Varty & Popejoy, 2020). As pediatric providers are having to routinely plan, design, implement, and evaluate transition plans for SCD patients the need for provider training, education, and guidance in this area is now recommended (Bryant et al., 2015; Brown & Sobota, 2016).

Much research has been done on pediatric transition to adult care, and the conclusion of this research is that more research, a standardized transition planning tool as well as provider preparation, education, and development are key components of successful transition (Bryant et al., 2015; Farooq et al., 2020; Travis et al., 2020). The hematology-oncology clinic does not currently have a standardized transition plan in place for sickle cell patients transferring from pediatric to adult care. For providers at the clinic, a clear understanding of the purpose of a standardized TPT, baseline knowledge of how to utilize it, and recognition of its values and benefits to transfer of care is necessary.

Review of Literature

The age of 12 has been proven as the most effective age at which to commence transition for sickle cell patients, with 18 being the ideal age for completion of transition and 21 being the recommended year to finalize transfer of care (GotTransition, 2021; Inusa et al., 2020). Many pediatric disease processes have standardized transition plans in place to guide transfer of care from solely pediatric specialty to adult care. Congestive heart failure, cystic fibrosis, and kidney disease patients are among those for whom transition plans have been extensively utilized and refined and have shown great benefit (Albert et al., 2015; Evans & Lopau, 2020). Transition for sickle cell disease patients on the other hand is not as refined and there is a need for more research on the subject (Kanter et al., 2020; Lanzkron et al., 2018; Farooq et al., 2020; Varty & Popejoy, 2019). The transition of sickle cell patients to adult care has proven a challenge and many patients experience an increase in complications soon after transfer to adult care (Kanter et al., 2020; Lanzkron et al., 2018; Renedo et al., 2019). According to Quinn et al., (2010) in a cohort of 940 subjects with 8857 patient-years of follow-up, it was noted that the majority of patient deaths occurred soon after the age of 18, when they transferred to adult care (Quinn et al, 2010). Factors that contribute to these poor outcomes include a shortage of specialized adult providers who are trained and educated on SCD and are comfortable seeing SCD patients, difficulties in care coordination, and loss of a primary medical home, and often times, loss of health insurance at the time of transfer (Kanter et al., 2020; Varty & Popejoy, 2020).

The use of transition tools is perceived by healthcare practitioners as helpful and supportive in providing direction on what to ask and how to glean transition readiness information from patients (Allen et al., 2020). Although transition tools are endorsed by providers as beneficial and valuable, a systematic review by Parfeniuk et al., (2020) showed that there is still slow movement towards establishing a standardized best practice measure for transition (Parfeniuk et al., 2020). Three of the six health system barriers to transition identified by Lanzkron et al., (2018) were inadequate training of primary and subspecialty practitioners, lack of appropriate training on treating child-hood conditions among adult-focused providers, and resistance of pediatric healthcare teams to initiate transition activities and transfer of care to adult services (Lanzkron et al., 2018). All of these barriers point towards a need for increased provider training and education with regards to transition, and guidance in effective transfer of care and transitioning of SCD patients to adulthood (Brown & Sobota, 2016; Varty & Popejoy, 2020). Given the lack of standardization in guidelines, gaps in care persist and lead to poor or unsuccessful transfer (Lanzkron et al., 2018; Loew et al., 2020). For providers, interactive education, seminars, webinars, and mentorship have proven very effective in promoting transition planning activities and building clinical skills necessary to effectively assist patients in the transition process (Lanzkron et al., 2018; National Institute for Children's Health Quality [NICHQ], 2020; Brown & Sobota, 2016). What promotes and guides engagement in active transition planning and is proven to be effective is a transition toolkit that standardizes the process (Lanzkron et al., 2018; Loew et al., 2020; Brown & Sobota, 2016). A transition planning tool has high potential for success because it encompasses multiple aspects of the patient's development and transition to adulthood, not solely the transfer of care (Morsa et al., 2018).

The primary goal of this quality improvement (QI) project was to create a standardized electronic medical record (EMR)-based tool to supplement the larger transition program at the organization. The aims of this quality improvement project were: 1) Adapt a standardized transition tool that pediatric hematology providers can use for addressing transition during visits with sickle cell disease patients. 2) Implement and utilize the transition tool in a pediatric hematology/oncology clinic for sickle cell transition planning. 3) Evaluate utilization of the transition tool. 4) Evaluate provider satisfaction with transition tool utilization.

Approach to the Conduct of the Project

This quality improvement project was part of an overarching larger project at an academic institution. The quality improvement initiative was piloted in the Hematology-Oncology clinic. The Hematology-Oncology department consists of 17 physicians. There are four social workers assigned to both outpatient and inpatient settings. Of these providers, two hematologists, a social worker, and a few medical assistants were primarily involved in the quality improvement (QI) project. Transition issues have been a topic of discussion at the organization for many years and a transition committee already exists, and a transition work group is actively meeting. The transition project was supported by the Department of Pediatrics, Primary Care Leadership (family medicine, internal medicine, pediatrics), and Children's and Women's leadership. Specialties supporting the project and willing to utilize the tool in their departments (in both pediatric and adult settings) include cardiology, endocrinology, GI, infectious disease, pulmonology, nephrology, neurology, psychiatry, hemophilia/spina bifida, occupational therapy, general pediatric and adolescent health, general family medicine, and general internal medicine.

Implementation of a transition tool is intended to standardize clinical practice, decrease cost and utilization for SCD patients, and enhance the organization's tripartite mission. A standardized transition tool has the potential to improve clinical care and put the patient first; it can create a framework for interprofessional and multidisciplinary education and development; and enhance research and system-wide improvement. Standardized transition has the potential to impact thousands of patients age 12-24 years old, many of whom have chronic conditions.

The greatest barrier and challenge to this quality improvement project was getting organizational approval for building the Epic transition tool. A proposal presentation was given to the scheduling and IT committee, and the project was elected as third priority out of six total projects proposed. As third on the list of prioritized projects, likely completion of the build was not expected until late spring or early summer of 2021. A key factor which facilitated the acceptance of the proposal to build the tool was the ongoing organization-wide effort to increase transition activities and standardize transition across specialties. At the time of graduation and completion of this project the final Epic transition tool was still in queue to be built. The goal for this quality improvement timeline changed from creation of the final build and immediate implementation by spring of 2021 at the latest, to finalization of the smart-phrases and effective utilization of these to pilot future implementation of the Epic final build.

Sample Population

The intervention was specifically focused on pediatric sickle cell providers and their sickle cell patient population. The provider population included three outpatient providers seeing sickle cell patients. The small size of this provider population was consistent with the request of the department to pilot the tool in a small scope for sickle cell patients only at this time. Of the 16 or more providers in the department, the three engaged in project development and implementation worked most closely with the population of choice. The patient population included sickle cell disease patients aged 12-21 years old. The total patient population was 50 patients with sickle cell disease. Inclusion criteria was age 12-21 years and, a patient at the academic institution, which resulted in 35 patients who could participate in this quality improvement project. The exclusion criteria were lack of readiness to engage in transition planning, and age below twelve years old, which excluded 15 patients. The recruitment plan involved presenting the patients and family with a description of the transition program and tool and the reason and evidence behind starting to plan for transition early.

As for the protection of patients, medical information and all health data collected and utilized was de-identified and stored on an encrypted device. Additionally, all standard HIPAA policies and procedures in place at the organization were adhered to. The IRB reviewed this project and deemed it as exempt (Figure 1), and not human subject research. No additional protections were necessary for the implementation of this project.

Proposed Implementation

This project utilizes the Social Ecological Model of AYA Readiness for Transition (SMART) theoretical framework, which is validated as an effective model for transition (Mulchan et al., 2015). Kurt Lewin's theory of change is the change model referred to for this quality improvement initiative. The plan-do-study-act (PDSA) cycle was the chosen quality improvement process by which evaluation and improvement of project elements was accomplished. The process of unfreezing the system and readying for the change took place early on. The QI project, creating a standardized transition tool, was the planning and implementation of the change. Now that this step has taken place, reinforcement and integration is the final step in the change process to establish the refreeze stage of the change model. This last step will be well outside the scope of this project (Hussain et al., 2018).

Intervention

The primary focus of this quality improvement project and a primary element of the larger transition program consisted of creation and implementation of an electronic health record transition tool. Each PDSA cycle was approximately a month, followed by review of data and feedback on functionality and areas for improvements and modifications. After completion of changes the smart-phrases and resources were again implemented on patients meeting the criteria for transition. After a 30-day period, review of the data and utility occurred and was followed by further improvements and changes. Once adequately adapted and functional the smart-phrases and resources were ready to submitted to the Epic build team for the final build.

PDSA cycle one involved the initial steps to transition planning including deciding on which supplemental transition planning items to include in the tool build. The team agreed on a transition to adult services policy and timeline as well as a readiness assessment developed for children 12-21 years old with sickle cell disease seen in the pediatric hematology oncology clinic. The introductory resources were built into the EMR as smart-phrases as the first PDSA cycle. The policy and timeline were adapted from Texas Childrens Hospital transition program and the GotTransition guidelines for a comprehensive transition. Once these were built into the EMR they were functionalized to be linkable to the patients MyChart, or printed and given to the patient during a visit.

PDSA cycle two planning commenced with designing of the readiness assessments and core transition question smart-phrases. Once the smart-phrase design and layout were agreed upon by the team, building of the smart-phrases commenced. It was agreed that the readiness assessment smart-phrases would be built into the EMR as two separate surveys, one for the patient (Figure 2) and one for the caregiver (Figure). Design of the readiness assessments involved building out the question sets into Epic followed by addition of the responses to each question. There were 32 items in the initial build of the readiness assessments. Additionally, the patient survey scoring (Figure) guide was built into the EMR, and the adult survey scoring guide (Figure) was also built into the EMR.Next was the building of the transition core questions. Again, the question sets were built into the EMR followed by addition of the responses. A total of 13 questions (Figure) were included in the core question smart-phrase. After building the smart-phrases the team was asked to review them for any inconsistencies in questions, correct formatting, and decide whether hyperlinks for educational resources would be incorporated. After review of the smart-phrases the team agreed to split the core transition questions into sub-categories in order to hone in on specific areas of weakness for patients completing transition planning. This involved rearranging some of the questions under specific topics and creating topic headings for each group of questions. Upon completion of this change the team was notified and the new arrangement and topic headings were reviewed, and additional changes were incorporated to simplify the topic headings making them more patient and family friendly. Additionally, the team also decided to add an additional eight survey items to each of the readiness surveys. These additional items were to include patient demographic data and caregiver demographic data as part of the survey. After this, there was a total of 40 items on the surveys. The team was given time to review the new surveys and provide additional feedback.

PDSA cycle three involved determining the need for the additional resources and education modules for each question in the core transition questions smart-phrase. After meeting and planning the team agreed to incorporate both hyperlinks and educational modules to each question as well as a resource library as a primary component of the transition tool. Over 80 transition handouts, resources and modules were adapted from St. Jude's sickle cell program and Texas Children's Sickle cell program to be built into the EMR tool (St. Jude Children's Research Hospital, 2021; Texas Children's Hospital, 2021). After review of these resources the team realized more than 50% of them did not apply to their specific region as many links were focused on resources available in the original sites where these programs were located. As a result, the team collected and reviewed additional resources and agreed on a set of combined resources and modules to be included in the final portion of the EMR build. Ultimately, approximately 70 handouts, modules, and resources were incorporated into the EMR smart-phrase build. The educational links and modules specific to each core transition question were built into the core question smart-phrase. The additional resources for transition were built into their own smart-phrase as the start of an EMR-based resource library for transition.

The collection of all these elements makes up the transition planning tool (TPT). For most TPT core questions, additional educational support materials were adapted from the two institutions, and linked to each topic area of transition. Once patients and family presented for a visit, they were provided with the transit policy and timeline, and then they completed a readiness survey. This data was transcribed in the EMR and used to guide additional transition planning. When a patient came in for a routine appointment transition planning was made part of the appointment. A short 5-10-minute segment was allotted for reviewing readiness assessment scores, and answering one or more transition question utilizing the TPT core questions smart-phrase within Epic. Patients were provided with educational modules pertinent to areas of weakness identified in their transition appointments. The last step in the implementation and effective utilization of this quality improvement project involved training providers on the Epic TPT, and how to create transfer notes.

Measures

Measurement of data and findings consisted of assessing the percentage of eligible patients who were asked transition questions, percentage of hematology visits where the transition tool was used, percentage of hematology providers who utilized the transition tool during the project period, and proportion of SCD patients who transferred and established care with an adult hematology provider during the project period. Data was collected utilizing the

EMR, and reviewing the sickle cell patient clinic visits, emergency department (ED) visits, and admissions. This data was inputted into an excel spreadsheet. Once it was noted that patients met the age criteria, transition planning was addressed during the patient encounter. The user initiating transition planning was identified by title (physician, registered nurse, medical assistant, social work, etc.) through review of the EMR encounter. The responses to transition questions were reviewed to determine what percentage of transition questions were addressed. Lastly, the percent change in provider engagement in transition activities from before the project implementation to after was measured using a standard Likert scale questionnaire (Figure) adapted with permission from Texas Children's Hospital (Polit & Tatano, 2017; Texas Children's Hospital, 2021).

Accuracy of collected patient data was ensured through careful review of the EMR by at least two members of the transition project team and compared for accuracy and validity. The goal was to ensure that the transition tool was intentionally utilized for all data points identified from an encounter; that the provider utilizing the tool was accurately categorized; the number of transition questions addressed were accurately documented; and that the patient met the age and disease criteria for transition planning.

Ethical Considerations

Some ethical considerations during this quality improvement (QI) initiative included but were not limited to, protection of patient healthcare information, and patient privacy. Use of the TPT introduced additional and sometimes new patient information to many more members of the multidisciplinary team. Extra caution was taken to protect such information, and not use it in a way that negatively impacted the patients care (Hergenroeder et al., 2016). Lastly, in the process of collecting data and reviewing responses to transition questions, no further exploration into the patient's chart to "learn more" about their involvement in the plan of care was ever undertaken. Adding this additional layer of medical care provided an opportunity for such violations of patient privacy to take place. As transition intertwines with many other aspects of the patient's medical care, discipline was and continues to be necessary to prevent such breeches of privacy. Those accessing patients' charts for transition, not providing direct or immediate care to the patient, need to be diligent to do so only for the purpose of reviewing transition focused patient information, not "browsing" the chart. It is clear that with this new tool, there were and are ethical considerations such as protection of collected patient data, amongst others. The hope is that in the hands of all providers this tool will provide a benefit to patients and contribute to improvement of care, not harm.

Projected Costs

The smart-phrases were created by a doctor of nursing practice (DNP) student at no cost, utilizing the validated questions from Got Transition and the TCH transition tool. TCH granted permission for use of multiple elements of their transition program including but not limited to the transition planning tool build guidelines, smart phrases, adapted Got Transition questions, Epic flowsheets, and Epic transition tool build infrastructure at no cost.

The EMR final tool build team consists of one analyst and one informaticist. The total number of build hours needed to complete this build is estimated to be 125 hours with the two IT specialists. So, 125 hours of build time and an analyst and informaticist salary for that time were the projected costs for the EMR build. Additional costs considered which were not defined or realized included, education and training for providers, need for supplemental equipment (iPad or tablets in the outpatient setting to allow for synchronization of transition data into the EMR, printing and distribution of transition resources), and need for data analysis services.

Implementation of Project

Plan-Do-Study-Act (PDSA) cycles were utilized to monitor, track, and guide improvements in the implementation and functionality of the smart-phrases and supplemental resources (Institute for Healthcare Improvement, 2019). As implementation of this QI project involved continual review, evaluation, and change to meet the future needs of a large population of providers and patients, the PDSA framework seemed to be the most fitting as it centers on the method of analyzing, adapting, and executing change to bring about improvement in a process. Development of the transition tool consisted of creating Epic smart-phrases. The smart-phrases were made in advance, during the waiting period for scheduling and approval of the final build, and were tested and refined. Modifications to the core questions and attached resources were made based on the patients' response to the transition question/resources as well as the provider experience in executing the transition planning via the EMR-based tool.

The initial Plan-Do-Study-Act (PDSA) cycle involved designing the smart-phrases and including the key introductory components of the transition process: policy, timeline, and readiness assessment (for the patient and the caregiver each to complete).

PDSA cycle two, the smart-phrases for the core transition questions and readiness assessment were created and subheadings added to separate questions by topic area. Epic smart-phrases were constructed using the primary questions followed by the established responses to the questions and then a space for educational materials and resources was created below the question and answer. 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?” etc. were intended to guide the interaction between the provider and the patient. The respondent either answered the question adequately or required further education.

After creation of the smart-phrases, PDSA cycle three involved addition of educational modules and resources. These additional resources were to supplement patients’ learning and mastery of the disease and transition skills, and were adapted with permission from St. Jude-Children’s Research Hospitals sickle cell transition E-learning program (STEP), and Texas Children’s Hospital (TCH) ((St. Jude Children's Research Hospital, 2021; Texas Children's Hospital, 2021). Education occurred in a three-pronged strategy: an explanation of the answer to a transition question was given, homework was provided, and a re-assessment occurred at subsequent visits.

Successful health care transition (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. A subset of questions was available to use with parents/caregivers whose children were developmentally unable to participate. During the project period no participants fit the definition of developmentally unable to participate so this subset of questions was not utilized. The TPT also allowed providers to document health care transition (HCT) preparation across services (GotTransition/Center for Healthcare Transition, 2014; Wiemann et al., 2015).

Review of the smart-phrases and testing in the patient environment was done together with two hematologists, a social worker, and the registered nurses and medical assistants on the hematology-oncology unit and led to some key realizations. During the implementation period there was a severe shortage of support in developing the components of the tool. In attempts to acquire more help the team worked to bring on a social work student or RN student to assist with key elements such as reviewing educational resources and modules, but were not able to get this additional help. Determining the hours of work required to complete each component of the tool and pursuing support before starting the process would have been a valuable first step. Secondly, there was a limited understanding of the organizational process for approving and beginning the build of an EMR-based tool. Again, preparation of a proposal presentation and approval of the transition tool for build well in advance of the piloting phase via the smart-phrases would have proven beneficial for timing and execution since the intent was to use the final build during the piloting phase. Repeat PDSA events were completed until the smart-phrases were ready for final production, and build. The official build of the TPT was intended to be the final PDSA cycle, but was not realized during the project timeframe, due to the time and resource constraints within the organization.

Outcomes/Results

Given the four-month timeframe for project completion and the small population size, the data for the project period is limited. Other reasons for a small data pool include the small population of sickle cell patients at the academic center where the study took place. No patients successfully transferred care during this project period due to the limited timeframe and small population. The patients and family agreed to engage in transition planning, and the transition readiness assessment and other necessary components were used to guide initial transition planning. Of the 35 patients who met the criteria for inclusion in transition planning, 12 (34%) had clinic visits during the project period. Of these 12 patients, two (16.6%) opted out of core questions due to plans to move out of state, one patient (8.3%) was unable to participate due to a pain crisis during the visit, and one patient (8.3%) was unable to participate due to lack of time during the visit. Of the 12 that were seen during the project period, eight (67%) completed core transition questions, for a 67% response rate. A total of eight successful instances of tool utilization were realized, a 67% utilization rate. With regards to the percentage of hematology visits where the transition tool was used, there were 12 total visits out of 35 eligible patients but the tool was utilized in only 8 of these visits. So, 67% of patient visits occurring during the project period involved transition planning using the tool. The percentage of eligible patients (8 of the 35 eligible) who were asked transition questions was ~23%. A summary of these results can be found in Figure .

The time frame for addressing transition using the core questions impacted the amount of data that could be collected in the project timeframe. The timeline for transition required that a readiness assessment be completed first and reviewed. After this step the patient would then have a follow-up visit to discuss the readiness scores and begin transition planning utilizing the core questions. As can be seen by the limited data, most of the patients who had visits during the project period did not have follow-up visits to discuss readiness scores and utilize the core question set within the project timeframe. This was dependent in part on the patient, as some older and more mature transition-ready patients may complete all 13 questions in one or two visits, while others may answer one or two questions per visit or not get beyond discussing their readiness assessment score. Also, the timeframe for follow-up played a part in this as some patients had shorter intervals to follow-up and others had much longer.

There are 16 ordering providers on the hematology oncology unit, and four social workers who can provide transition planning. Two ordering providers and one social worker were involved in the project and given access to the tool. All three of these individuals utilized the tool. The percentage of hematology providers who utilized the transition tool during the project period was 100% (Figure). A provider self-assessment questionnaire directed at gauging the percent change in provider engagement in transition before and after implementation of the transition planning tool showed that for all 3 providers there was a modest increase in transition planning and engagement in transition activities. Pre-implementation of the TPT provider one gave a score of 19 for engagement in transition planning activities, and post-implementation that score went up to 22. This was a 15.8% increase in engagement in transition activities for provider one. Pre-implementation of the TPT provider two gave a score of 19 for engagement in transition planning activities, and post-implementation that score went up to 23. This was a 21% increase in engagement in transition activities for provider two. Pre-implementation of the TPT provider three gave a score of 12 for engagement in transition planning activities, and post-implementation that score went up to 21. This was a 75% increase in engagement in transition activities for provider three. Given these results it is clear that the intervention positively impacted engagement in transition activities for all providers involved (Figure).

The primary reason for such a small population of utilizers was lack of a finalized Epic tool. The predicted time from the proposal presentation to get the tool built was not accurate, and as a result the build was not completed in time to be tested during this QI project. If the final tool was built into the EMR, the additional providers would have had access to them. Due to the lack of a final build, the primary utilizers were key stakeholders who were invested in testing and refining the smart-phrases for the final build. The proportion of SCD patients who transferred and established care with an adult hematology provider during the project period was 0%. This was an expected finding as transition completion and transfer of care takes much longer than the four-month project period allowed. Of the eight patients seen, one patient began the initial steps to transfer of care, but did not complete transfer before the end of the QI project. As a result of the delay in building the tool (the predicted cost incurring step) in to the EMR, the QI project incurred no costs to the organization in its initial piloting phase.

Implications for Practice

Utilization of the SMART model has been validated as an effective means for transitioning pediatric patients to adult services. Evaluation of outcomes will determine the effectiveness of this practice innovation in improving transition planning and providing a standardized tool for transition. The clinical implications of this practice innovation are an improved and standardized transition process for providers, improved transition for SCD patients, potential for a decrease in acute care service utilization, possible decrease in mortality and morbidity, and increased utilization of adult care services by SCD patients.

The primary limitation was that completion of the tool and finalization of Epic customization did not occur during this project period. A challenge in developing the project was compiling the necessary patient handouts and resources for each core question and getting review and approval by the hematology-oncology team in a timely manner. Due to the difficulty in coordinating everyone's schedules it took a length of time for the resources and handouts to be reviewed. The initial review of the handouts was limited to just one provider and it took an additional three months for the other two providers to find the time to review the resources and handouts. As a result, the resources and handouts were not incorporated into the core questions until the last month of the project period. Lack of a comprehensive library of patient resources and handouts led to a decreased ability to adequately track utilization of educational resources and handouts by patients. The primary reason for this was lack of time for the providers and the inability to coordinate and find time outside of established work responsibilities. A final limitation to this quality improvement project is that the small sample size and small batch of data was not representative of the sickle cell population as a whole, or generalizable to a larger population. All limitations considered, this QI project sheds light on the impact of a standardized transition toolkit on increased engagement in transition planning and transition activities by providers. Given that this project utilized an incomplete and yet to be finalized version of the transition toolkit, included only 35 patients, 3 providers, and took place over a 4-month period these are very notable findings. Even with these barriers to implementation and execution, there was a significant improvement in transition planning amongst providers. The clinical implications of these findings are noteworthy.

Next Steps

Recommendations for future research on this topic should address patient education, emotional maturity, and developmental preparedness for transition planning (Calhoun et al., 2018; Crosby et al., 2015). Furthermore, providers must begin and continue to effectively utilize standardized transition tools to guide transition planning for youth with special healthcare needs (Frost et al., 2016; Wiemann et al 2015). Future aims and efforts on SCD patient transition in the hematology-oncology clinic should address patient education and preparedness for transfer to adult care. Future expansion of the population utilizing the intervention includes physicians, nurse practitioners, and physician assistants. Future improvements on QI transition projects should incorporate the final build of the EMR-based tool for piloting. Lastly, next steps should include hiring a provider whose sole focus is development, improvement, utilization, and evaluation of transition at the clinic. On a larger skill, next steps should include a designated transition medicine provider to direct coordination and development of future transition efforts at the organization level.

Conclusion

The results of this QI project reflect the findings in the literature. During this project, as is noted in the literature, there was a slow adoption of standardized transition planning within the clinic (Ibrahim et al., 2020; Leake et al., 2020; Sobota et al., 2011; Wiemann et al., 2015). Providers lacked experience and exposure to a standardized transition tool and process. The conclusion of the findings in this project echo that of the literature. Pediatric providers need a standardized process by which to effectively assess for key indicators of transition readiness. Experience is needed with engaging in use of a transition tool to plan transition, and follow-up with patients to guarantee successful transfer of care (Lanzkron et al., 2018; Loew et al., 2020; National Institute for Children's Health Quality (NICHQ), 2020). Lastly, when provided with a standardized process, providers showed an increase in engagement in transition planning and transition related activities (Ibrahim et al., 2020; Lanzkron et al., 2018; Wiemann et al., 2015). In completing this QI project, notable advancements in transition planning were spurred within the hematology oncology clinic as well as the organization-wide scope of transition medicine at the academic institute. New efforts and many new stakeholders contributed to start developing and implementing standardized transition in multiple subspecialties. Additionally, the first ever EMR-based transition tool was approved for an Epic build at the institution. Building a standardized tool is the next key step that must take place for true standardization of care for SCD patients, and all patients needing structured transition planning. Future successful in transition will include continued buy-in and engagement of key stakeholders within the hematology clinic and the academic institution.

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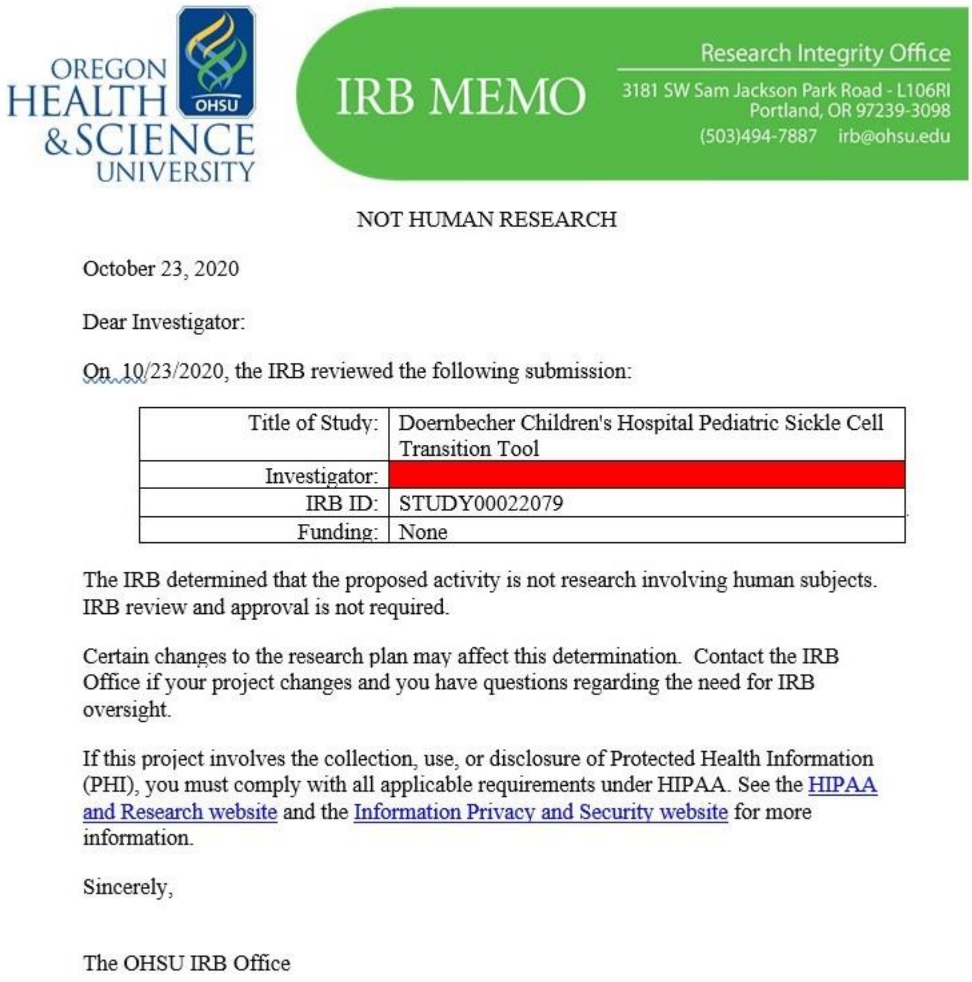
Figure 1

IRB Determination



OREGON HEALTH & SCIENCE UNIVERSITY
OHSU

IRB MEMO

Research Integrity Office
3181 SW Sam Jackson Park Road - L106RI
Portland, OR 97239-3098
(503)494-7887 irb@ohsu.edu

NOT HUMAN RESEARCH

October 23, 2020

Dear Investigator:

On 10/23/2020, the IRB reviewed the following submission:

Title of Study:	Doernbecher Children's Hospital Pediatric Sickle Cell Transition Tool
Investigator:	[redacted]
IRB ID:	STUDY00022079
Funding:	None

The IRB determined that the proposed activity is not research involving human subjects. IRB review and approval is not required.

Certain changes to the research plan may affect this determination. Contact the IRB Office if your project changes and you have questions regarding the need for IRB oversight.

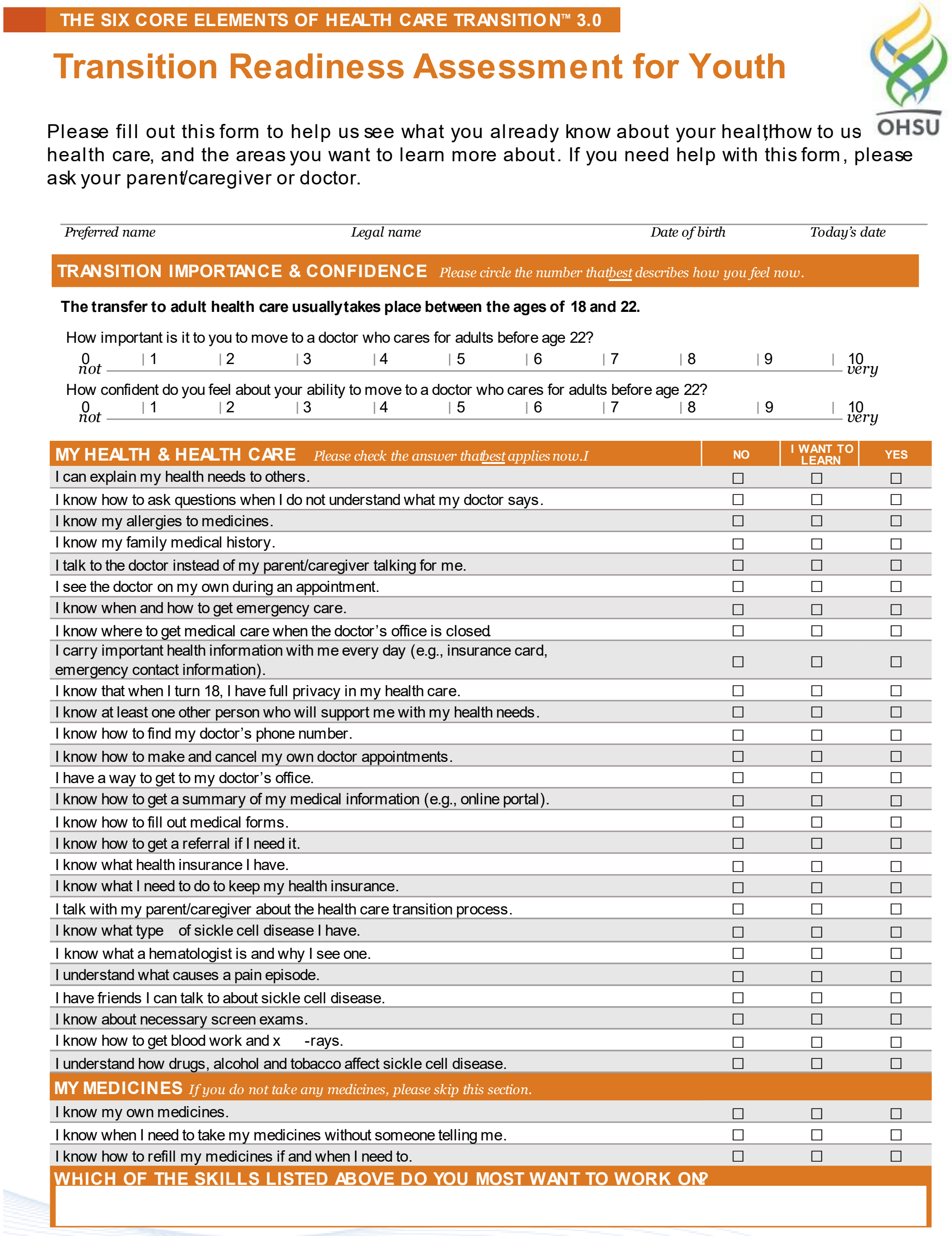
If this project involves the collection, use, or disclosure of Protected Health Information (PHI), you must comply with all applicable requirements under HIPAA. See the HIPAA and Research website and the Information Privacy and Security website for more information.

Sincerely,

The OHSU IRB Office

Figure 2

Youth Readiness Assessment



THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Transition Readiness Assessment for Youth

OHSU

Please fill out this form to help us see what you already know about your health, how to us health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name *Legal name* *Date of birth* *Today's date*

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to you to move to a doctor who cares for adults before age 22?

0 *not* | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 *very*

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 *not* | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 *very*

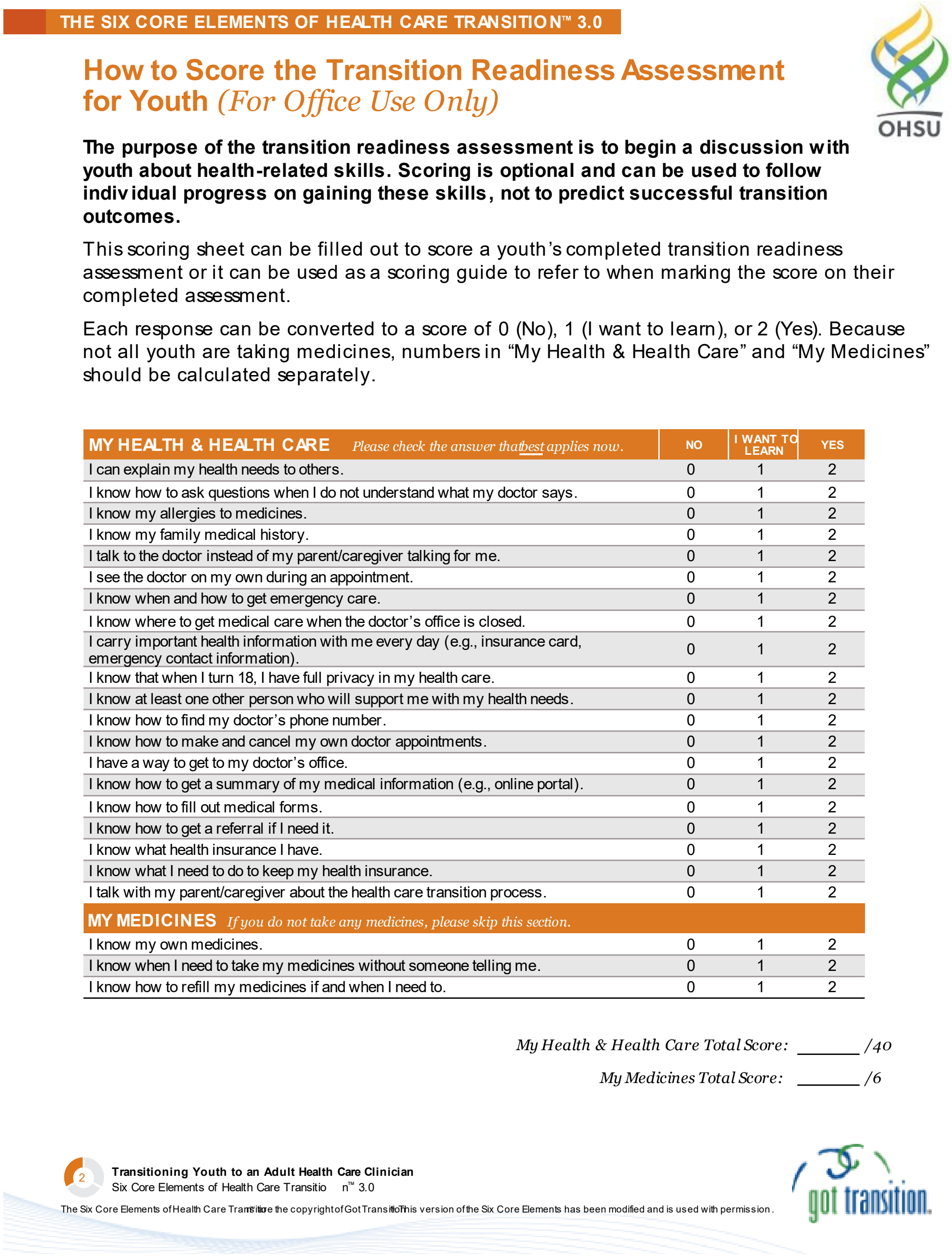
MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	☐	☐	☐
I know how to ask questions when I do not understand what my doctor says.	☐	☐	☐
I know my allergies to medicines.	☐	☐	☐
I know my family medical history.	☐	☐	☐
I talk to the doctor instead of my parent/caregiver talking for me.	☐	☐	☐
I see the doctor on my own during an appointment.	☐	☐	☐
I know when and how to get emergency care.	☐	☐	☐
I know where to get medical care when the doctor's office is closed.	☐	☐	☐
I carry important health information with me every day (e.g., insurance card, emergency contact information).	☐	☐	☐
I know that when I turn 18, I have full privacy in my health care.	☐	☐	☐
I know at least one other person who will support me with my health needs.	☐	☐	☐
I know how to find my doctor's phone number.	☐	☐	☐
I know how to make and cancel my own doctor appointments.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know how to get a summary of my medical information (e.g., online portal).	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get a referral if I need it.	☐	☐	☐
I know what health insurance I have.	☐	☐	☐
I know what I need to do to keep my health insurance.	☐	☐	☐
I talk with my parent/caregiver about the health care transition process.	☐	☐	☐
I know what type of sickle cell disease I have.	☐	☐	☐
I know what a hematologist is and why I see one.	☐	☐	☐
I understand what causes a pain episode.	☐	☐	☐
I have friends I can talk to about sickle cell disease.	☐	☐	☐
I know about necessary screen exams.	☐	☐	☐
I know how to get blood work and x-rays.	☐	☐	☐
I understand how drugs, alcohol and tobacco affect sickle cell disease.	☐	☐	☐
MY MEDICINES *If you do not take any medicines, please skip this section.*			
I know my own medicines.	☐	☐	☐
I know when I need to take my medicines without someone telling me.	☐	☐	☐
I know how to refill my medicines if and when I need to.	☐	☐	☐

WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?

Final patient readiness assessment QR code

Figure 3

Youth Survey Scoring Guide



THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

How to Score the Transition Readiness Assessment for Youth *(For Office Use Only)*

OHSU

The purpose of the transition readiness assessment is to begin a discussion with youth about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes.

This scoring sheet can be filled out to score a youth's completed transition readiness assessment or it can be used as a scoring guide to refer to when marking the score on their completed assessment.

Each response can be converted to a score of 0 (No), 1 (I want to learn), or 2 (Yes). Because not all youth are taking medicines, numbers in "My Health & Health Care" and "My Medicines" should be calculated separately.

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	0	1	2
I know how to ask questions when I do not understand what my doctor says.	0	1	2
I know my allergies to medicines.	0	1	2
I know my family medical history.	0	1	2
I talk to the doctor instead of my parent/caregiver talking for me.	0	1	2
I see the doctor on my own during an appointment.	0	1	2
I know when and how to get emergency care.	0	1	2
I know where to get medical care when the doctor's office is closed.	0	1	2
I carry important health information with me every day (e.g., insurance card, emergency contact information).	0	1	2
I know that when I turn 18, I have full privacy in my health care.	0	1	2
I know at least one other person who will support me with my health needs.	0	1	2
I know how to find my doctor's phone number.	0	1	2
I know how to make and cancel my own doctor appointments.	0	1	2
I have a way to get to my doctor's office.	0	1	2
I know how to get a summary of my medical information (e.g., online portal).	0	1	2
I know how to fill out medical forms.	0	1	2
I know how to get a referral if I need it.	0	1	2
I know what health insurance I have.	0	1	2
I know what I need to do to keep my health insurance.	0	1	2
I talk with my parent/caregiver about the health care transition process.	0	1	2
MY MEDICINES *If you do not take any medicines, please skip this section.*			
I know my own medicines.	0	1	2
I know when I need to take my medicines without someone telling me.	0	1	2
I know how to refill my medicines if and when I need to.	0	1	2

My Health & Health Care Total Score: _______ /40

My Medicines Total Score: _______ /6

2

Transitioning Youth to an Adult Health Care Clinician
Six Core Elements of Health Care Transition™ 3.0

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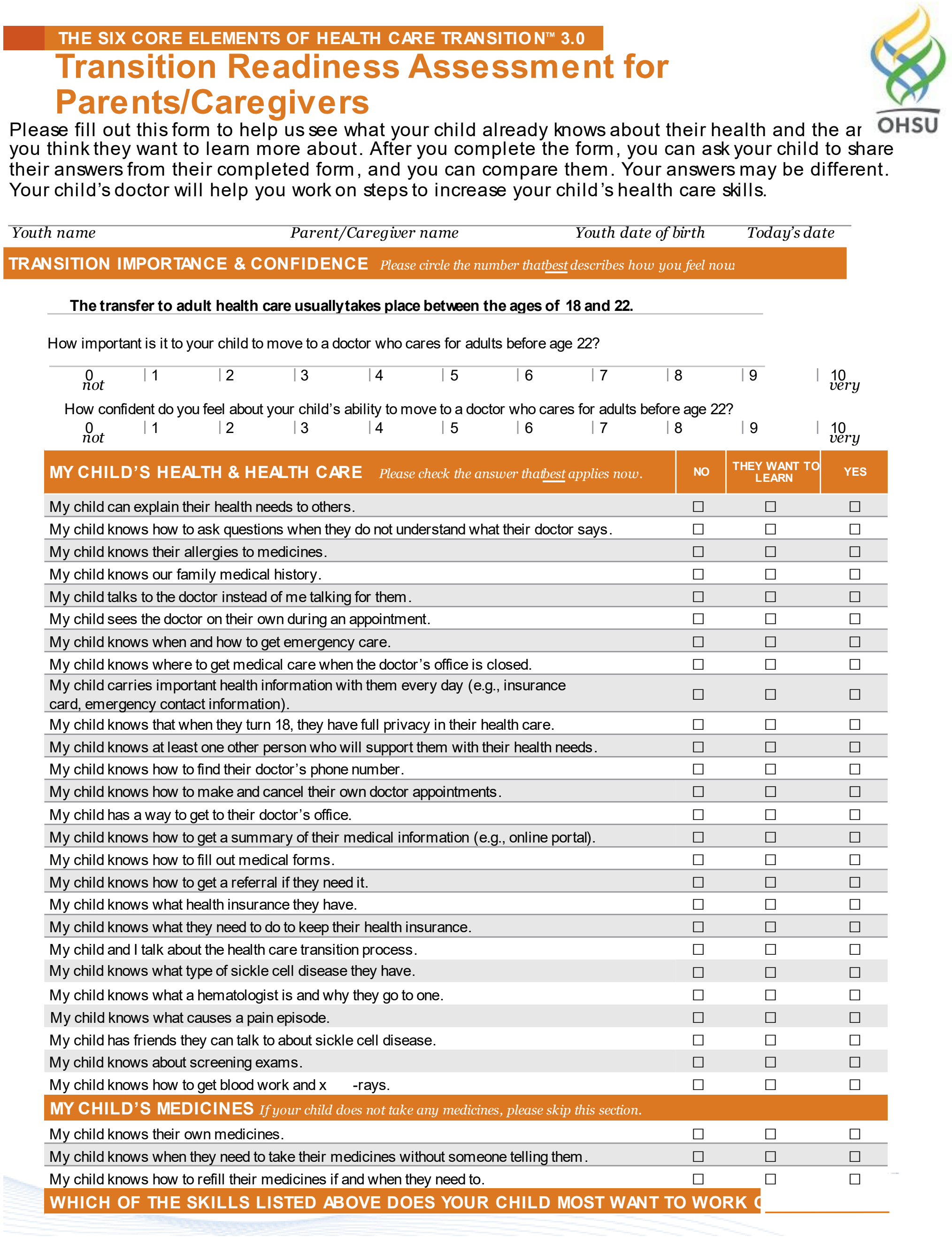
got transition.

Figure 4

Caregiver Readiness Assessment



THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Transition Readiness Assessment for Parents/Caregivers

OHSU

Please fill out this form to help us see what your child already knows about their health and the ar you think they want to learn more about. After you complete the form, you can ask your child to share their answers from their completed form, and you can compare them. Your answers may be different. Your child's doctor will help you work on steps to increase your child's health care skills.

Youth name	*Parent/Caregiver name*	*Youth date of birth*	*Today's date*

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to your child to move to a doctor who cares for adults before age 22?

0 *not*	1	2	3	4	5	6	7	8	9	10 *very*

How confident do you feel about your child's ability to move to a doctor who cares for adults before age 22?

0 *not*	1	2	3	4	5	6	7	8	9	10 *very*

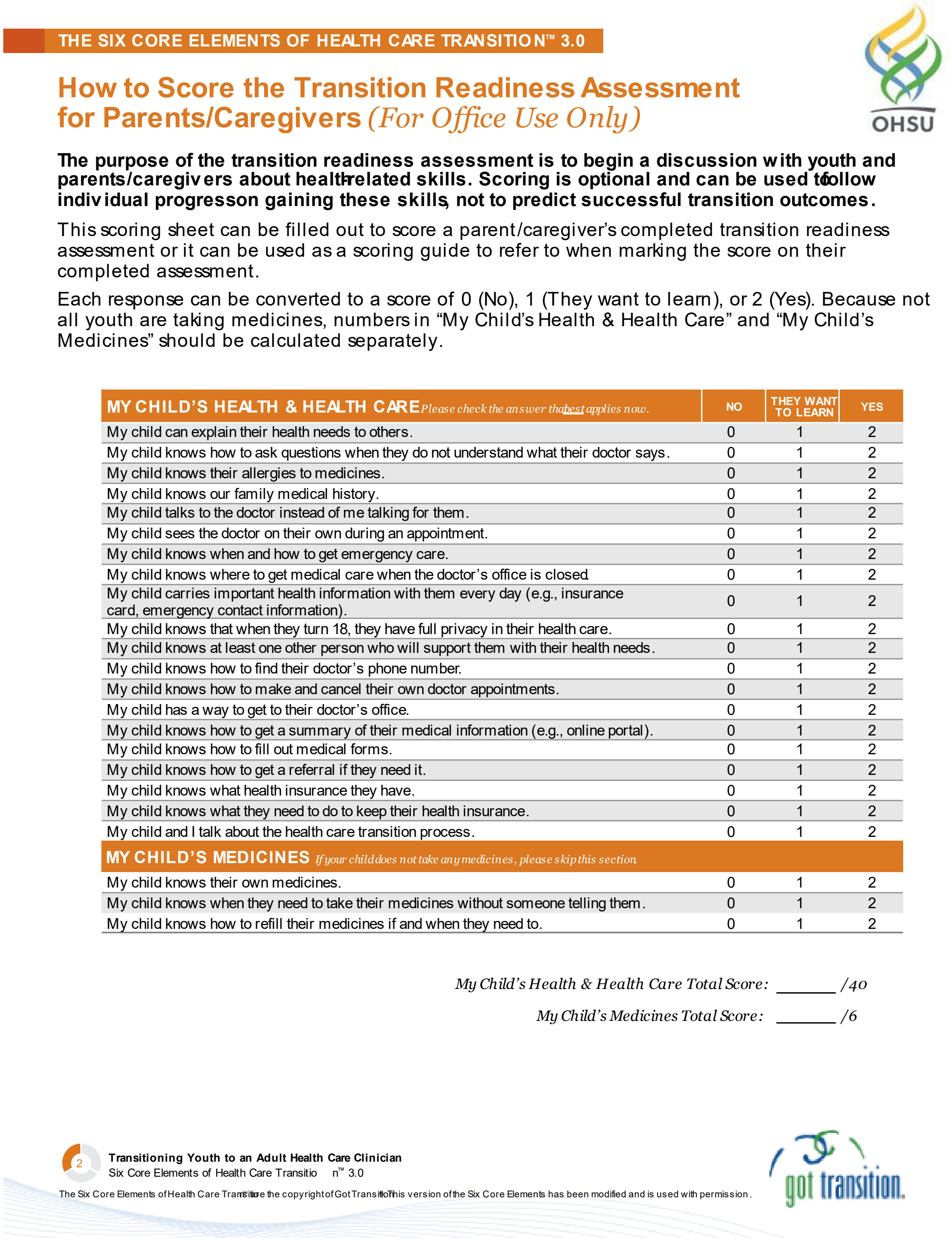
MY CHILD'S HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	THEY WANT TO LEARN	YES
My child can explain their health needs to others.	☐	☐	☐
My child knows how to ask questions when they do not understand what their doctor says.	☐	☐	☐
My child knows their allergies to medicines.	☐	☐	☐
My child knows our family medical history.	☐	☐	☐
My child talks to the doctor instead of me talking for them.	☐	☐	☐
My child sees the doctor on their own during an appointment.	☐	☐	☐
My child knows when and how to get emergency care.	☐	☐	☐
My child knows where to get medical care when the doctor's office is closed.	☐	☐	☐
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	☐	☐	☐
My child knows that when they turn 18, they have full privacy in their health care.	☐	☐	☐
My child knows at least one other person who will support them with their health needs.	☐	☐	☐
My child knows how to find their doctor's phone number.	☐	☐	☐
My child knows how to make and cancel their own doctor appointments.	☐	☐	☐
My child has a way to get to their doctor's office.	☐	☐	☐
My child knows how to get a summary of their medical information (e.g., online portal).	☐	☐	☐
My child knows how to fill out medical forms.	☐	☐	☐
My child knows how to get a referral if they need it.	☐	☐	☐
My child knows what health insurance they have.	☐	☐	☐
My child knows what they need to do to keep their health insurance.	☐	☐	☐
My child and I talk about the health care transition process.	☐	☐	☐
My child knows what type of sickle cell disease they have.	☐	☐	☐
My child knows what a hematologist is and why they go to one.	☐	☐	☐
My child knows what causes a pain episode.	☐	☐	☐
My child has friends they can talk to about sickle cell disease.	☐	☐	☐
My child knows about screening exams.	☐	☐	☐
My child knows how to get blood work and x -rays.	☐	☐	☐
MY CHILD'S MEDICINES *If your child does not take any medicines, please skip this section.*			
My child knows their own medicines.	☐	☐	☐
My child knows when they need to take their medicines without someone telling them.	☐	☐	☐
My child knows how to refill their medicines if and when they need to.	☐	☐	☐

WHICH OF THE SKILLS LISTED ABOVE DOES YOUR CHILD MOST WANT TO WORK C

Final patient readiness assessment QR code

Figure 5

Caregiver Survey Scoring Guide



THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

How to Score the Transition Readiness Assessment for Parents/Caregivers *(For Office Use Only)*

The purpose of the transition readiness assessment is to begin a discussion with youth and parents/caregivers about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes.

This scoring sheet can be filled out to score a parent/caregiver's completed transition readiness assessment or it can be used as a scoring guide to refer to when marking the score on their completed assessment.

Each response can be converted to a score of 0 (No), 1 (They want to learn), or 2 (Yes). Because not all youth are taking medicines, numbers in "My Child's Health & Health Care" and "My Child's Medicines" should be calculated separately.

MY CHILD'S HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	THEY WANT TO LEARN	YES
My child can explain their health needs to others.	0	1	2
My child knows how to ask questions when they do not understand what their doctor says.	0	1	2
My child knows their allergies to medicines.	0	1	2
My child knows our family medical history.	0	1	2
My child talks to the doctor instead of me talking for them.	0	1	2
My child sees the doctor on their own during an appointment.	0	1	2
My child knows when and how to get emergency care.	0	1	2
My child knows where to get medical care when the doctor's office is closed.	0	1	2
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	0	1	2
My child knows that when they turn 18, they have full privacy in their health care.	0	1	2
My child knows at least one other person who will support them with their health needs.	0	1	2
My child knows how to find their doctor's phone number.	0	1	2
My child knows how to make and cancel their own doctor appointments.	0	1	2
My child has a way to get to their doctor's office.	0	1	2
My child knows how to get a summary of their medical information (e.g., online portal).	0	1	2
My child knows how to fill out medical forms.	0	1	2
My child knows how to get a referral if they need it.	0	1	2
My child knows what health insurance they have.	0	1	2
My child knows what they need to do to keep their health insurance.	0	1	2
My child and I talk about the health care transition process.	0	1	2
MY CHILD'S MEDICINES *If your child does not take any medicines, please skip this section.*			
My child knows their own medicines.	0	1	2
My child knows when they need to take their medicines without someone telling them.	0	1	2
My child knows how to refill their medicines if and when they need to.	0	1	2

My Child's Health & Health Care Total Score: _______ */40*

My Child's Medicines Total Score: _______ */6*

2 **Transitioning Youth to an Adult Health Care Clinician**
Six Core Elements of Health Care Transition™ 3.0

Figure 6

Core Transition Questions

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Patient Core Transition Questions (sample)

OHSU

TRANSITION PLANNING TOOL (TPT)

PATIENT CORE QUESTIONS AND INTERVENTIONS

1. **Tell me about your diagnosis. (Patient can communicate basic disease process)**

{Tell me about your diagnosis:22478}

Homework Activities: ST. Judes Modules:
What is Sickle Cell? Infographic
Sickle Cell and Me
Healthy Living and Sickle Cell

2. Tell me what signs you need to be aware of that indicate you are approaching an emergency situation with your diagnosis? How can you avoid the emergency? When do you call the doctor or go to the emergency room? (Patient can communicate basic signs/symptoms and plan of action in an emergent situation)

{Signs and symptoms of emergency:22479}

Healthy Living and Sickle Cell
Symptoms, Pain, and Infection
Other Complications of My Disease

Service can provide condition-specific handout about what indicates an emergency situation.

3. What number do you call in an emergency? Who are your doctors and how do you contact them? Do you have an In Case of Emergency (ICE) contact in your cell phone? (Patient can communicate 911 emergency number and appropriate contact information for all of his/her physicians. Patient has an ICE contact in his/her cell phone, if applicable)

{Making emergency call:22480}

Homework Activities: Important Healthcare Information
Important Healthcare Information (Spanish)

4. How do you schedule your doctor's appointments? (Patient can communicate how to schedule an appointment)

{Scheduling appointments:22481}

Homework Activities: Tracking Appointments
Tracking Appointments (Spanish)

5. Did you meet with your doctor without your parent and ask a question today? (Patient met with doctor without a caregiver present and asked an age appropriate question. A suggested topic could be "what would you like more information about or what are you concerned about?")

{Meet with doctor solo:22482}

Homework Activities:
Self-Advocacy

My Healthcare Questions
My Healthcare Questions (Spanish)

6. What are the names of your medications? What are they for? When do you take them? How much do you take? Are there any foods, beverages or other medications you should avoid when taking your prescriptions? (Patient can communicate name, action, dosing and contraindications of medications.)

3 **Transitioning Youth to an Adult Health Care Clinician**
Six Core Elements of Health Care Transition™ 3.0

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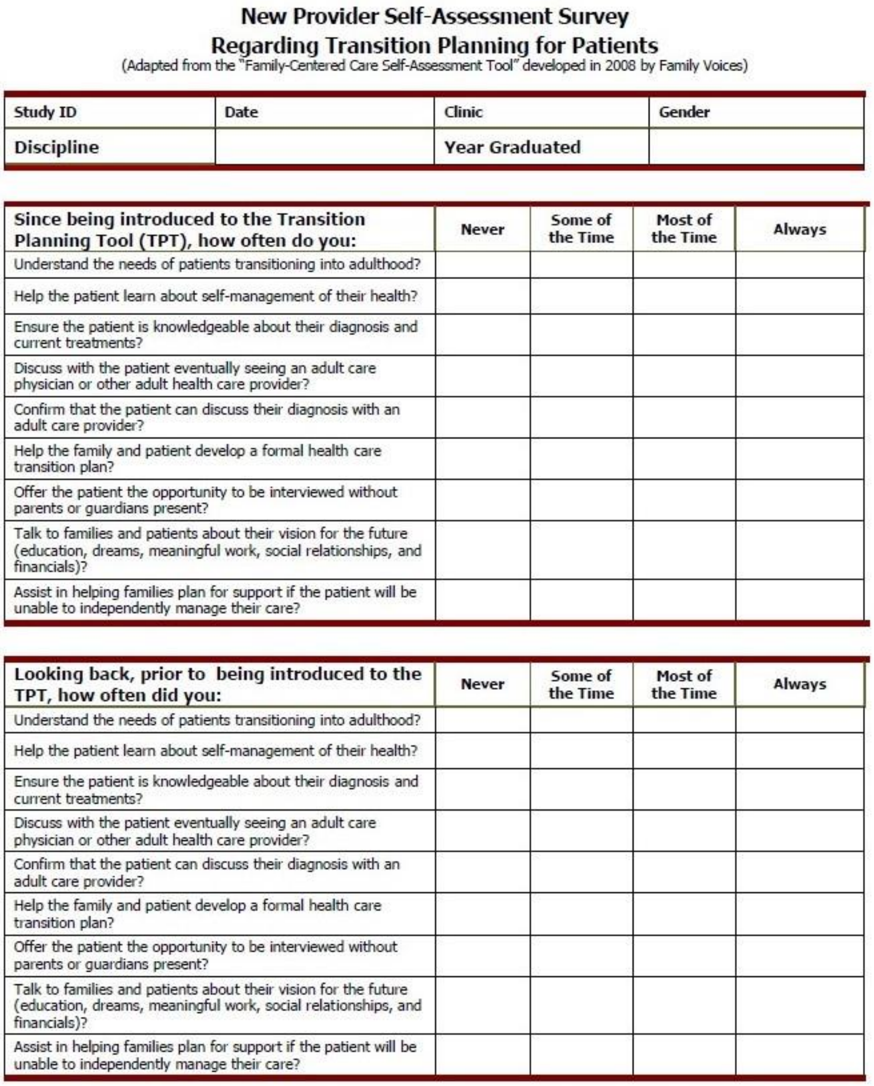
Full question set QR code

Figure 7

Provider Self-Assessment Survey



New Provider Self-Assessment Survey
Regarding Transition Planning for Patients
(Adapted from the "Family-Centered Care Self-Assessment Tool" developed in 2008 by Family Voices)

Study ID	**Date**	**Clinic**	**Gender**
Discipline		**Year Graduated**	

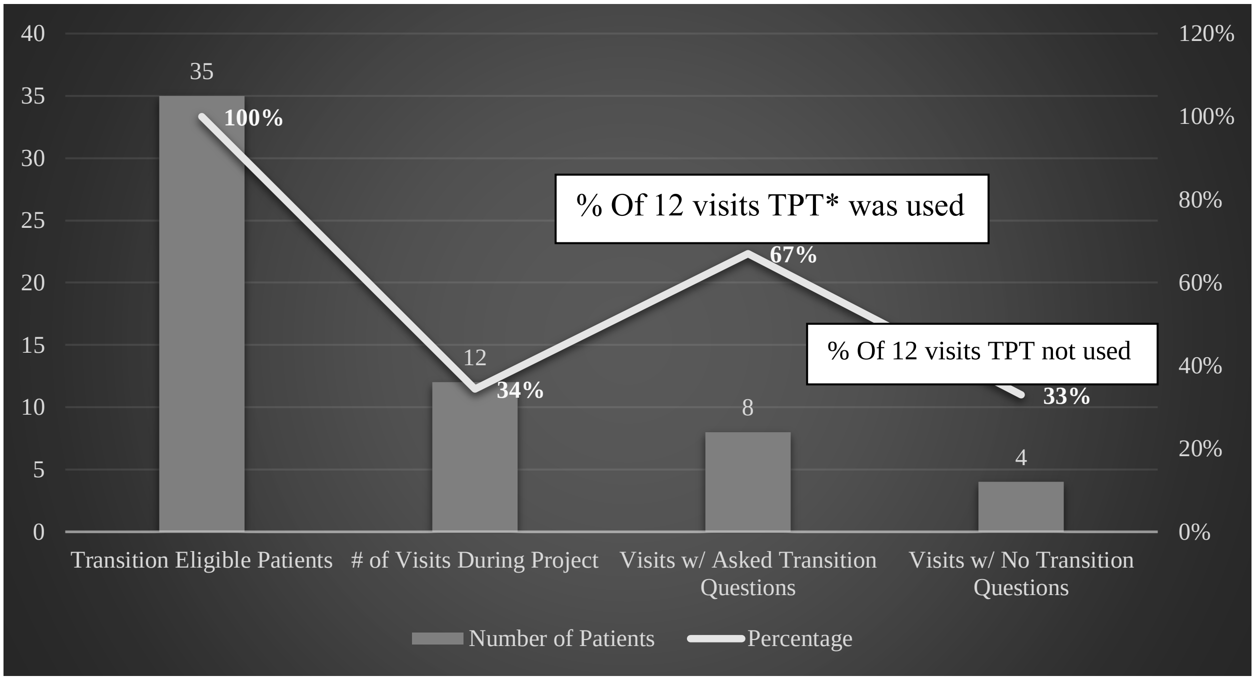
Since being introduced to the Transition Planning Tool (TPT), how often do you:	**Never**	**Some of the Time**	**Most of the Time**	**Always**
Understand the needs of patients transitioning into adulthood?				
Help the patient learn about self-management of their health?				
Ensure the patient is knowledgeable about their diagnosis and current treatments?				
Discuss with the patient eventually seeing an adult care physician or other adult health care provider?				
Confirm that the patient can discuss their diagnosis with an adult care provider?				
Help the family and patient develop a formal health care transition plan?				
Offer the patient the opportunity to be interviewed without parents or guardians present?				
Talk to families and patients about their vision for the future (education, dreams, meaningful work, social relationships, and financials)?				
Assist in helping families plan for support if the patient will be unable to independently manage their care?				

Looking back, prior to being introduced to the TPT, how often did you:	**Never**	**Some of the Time**	**Most of the Time**	**Always**
Understand the needs of patients transitioning into adulthood?				
Help the patient learn about self-management of their health?				
Ensure the patient is knowledgeable about their diagnosis and current treatments?				
Discuss with the patient eventually seeing an adult care physician or other adult health care provider?				
Confirm that the patient can discuss their diagnosis with an adult care provider?				
Help the family and patient develop a formal health care transition plan?				
Offer the patient the opportunity to be interviewed without parents or guardians present?				
Talk to families and patients about their vision for the future (education, dreams, meaningful work, social relationships, and financials)?				
Assist in helping families plan for support if the patient will be unable to independently manage their care?				

Note. Provider survey is intended to gauge the change in transition planning activities from pre-implementation to post-implementation of the transition planning toolkit. Scoring is from 1 to 4 with 1 = never, 2 = some of the time, 3 = most of the time, and 4 = always do the transition task.

Figure 8

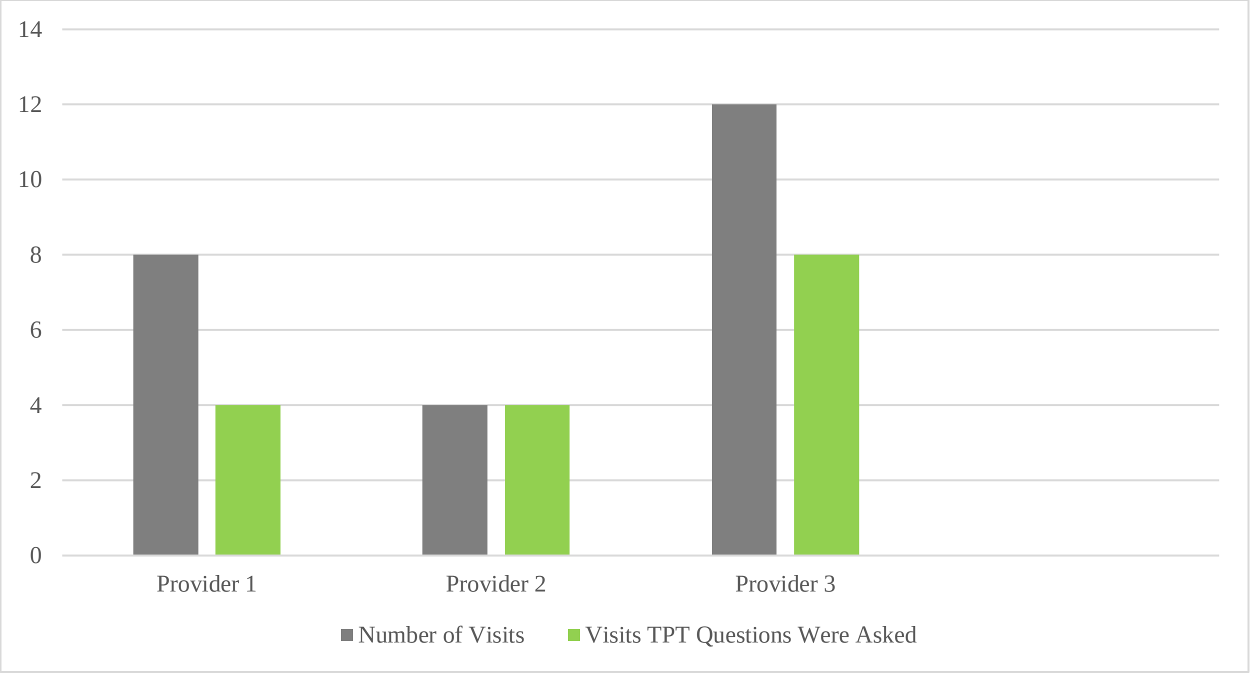
Patient Transition Planning Tool Utilization



Note. Transition tool utilization during project period reflects the total number of transition age patients in the clinic (35 or 100%) and number and percentage of patients who had visits during the project period (12 or 34%). Of the 12 that had visits during the project period, 8 engaged in transition planning (67% of visits) and 4 did not engage in transition planning (33% of visits). This data reflects that 67% of visits the tool was used, and the response rate was 67% (8 of 12 patients answered transition questions), and 33% of visits patients did not engage in transition planning. TPT = transition planning tool

Figure 9

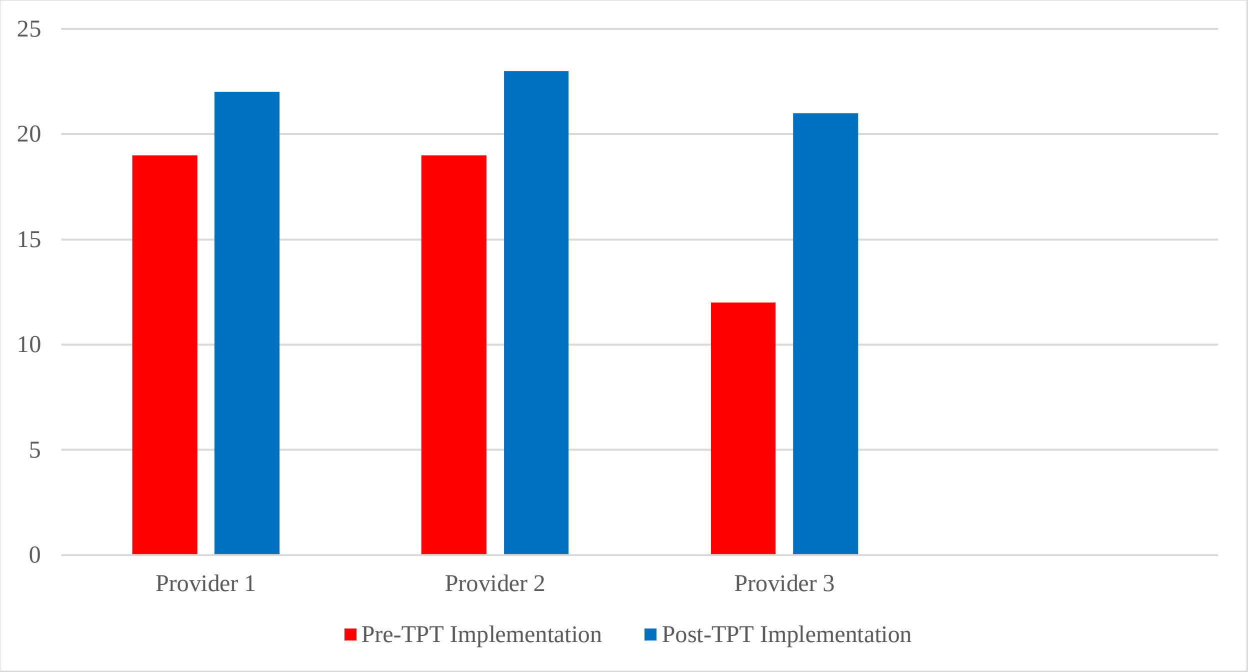
Provider Tool Utilization



Note. For a total of 3 providers there was 12 patient visits. Provider one saw 8 of these patients, but only used the transition planning tool 4 of those visits. Provider two saw 4 patients and used the transition planning tool at every visit. Provider three saw the same 12 patients (the 8 seen by provider 1 and the 4 seen by provider 2) and utilized the tool for 8 of those visits.

Figure 10

Provider Self-Assessment Survey Results



Note. For a total of 3 providers, the questionnaire scores showed an improvement from pre-implementation of the transition planning tool (TPT*) to post-implementation. This was reflective of increased engagement in transition planning and increased satisfaction with transition tool utilization. The smallest increase was 15.8% (provider 1), followed by a 21% (provider 2) increase, and the largest was 75% (provider 3).