

Running Head: Healthcare Transition Practices

Title: Differences in Health Care Transition Views, Practices, and Barriers Amongst North American Pediatric Rheumatology Clinicians from 2010 to 2018

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ABSTRACT

Objective: Since 2010, the rheumatology community has developed guidelines and tools to improve healthcare transition. In this study we aimed to compare current transition practices and beliefs among Childhood Arthritis and Rheumatology Research Alliance (CARRA) rheumatology providers with transition practices from a 2010 provider survey published by Chira et al.

Methods: In 2018, CARRA members completed a 25-item online survey about healthcare transition. Got Transition's™ Current Assessment of Health Care Transition Activities was used to measure clinical transition processes on a scale of 1 (basic) to 4 (comprehensive). Bivariate analyses were used to compare 2010 and 2018 survey findings.

Results: Over half of CARRA members completed the survey (217/396), including pediatric rheumatologists, adult- and pediatric-trained rheumatologists, pediatric rheumatology fellows, and advanced practice providers. The most common target age to begin transition planning was 15-17 (49%). Most providers transferred patients prior to age 21 or older (75%). Few providers used the American College of Rheumatology transition tools (31%) or have a dedicated transition clinic (23%). Only 17% had a transition policy in place, and 63% did not consistently address healthcare transition with patients. When compared to the 2010 survey, improvement was noted in three of twelve transition barriers: availability of adult primary care providers, availability of adult rheumatologists, and pediatric staff transition knowledge and skills ($p < 0.001$ for each). Nevertheless, the mean Current Assessment score was less than 2 for each measurement.

Conclusion: This study demonstrates improvement in certain transition barriers and practices since 2010, although implementation of structured transition processes remains inconsistent.

SIGNIFICANCE AND INNOVATION

- This 2018 survey of pediatric rheumatology providers demonstrates improvement in three transition barriers since 2010.
- Over the past eight years, the percentage of providers starting transition planning by age 12-14 increased from ~25% to more than 40%.
- Nevertheless, fewer than half of North American pediatric rheumatology clinics currently report using structured healthcare transition processes, highlighting the need for additional institutional resources for transition education and process improvement implementation.

INTRODUCTION

Health care transition (HCT) is defined by the Society of Adolescent Health and Medicine (SAHM) as “the planned process of moving from a child to an adult model of health care, with or without a transfer to a new clinician,” through a “process that addresses the medical, psychosocial, educational/vocational needs” of patients.^{1, 2} Structured HCT processes have been shown to improve patient satisfaction, continuity of care, adherence to care, and independence in medical care.³⁻⁵ Over the past two decades, HCT has become a growing area of focus for quality improvement efforts by national professional organizations, including the American College of Physicians (ACP) and the American Academy of Pediatrics (AAP), and the American Academy of Family Physicians, as well as multiple subspecialty organizations.⁶

The process of HCT should occur over time, beginning with increasing independence in self-management, progressing toward decreased parental involvement and the adoption of an adult approach to care, and continuing after transfer to adult health care clinicians.^{1,3,6-7} This journey is most successful when both pediatric and adult medical providers, as well as social workers, nurses, case managers, patients, families and others, share responsibility.^{1,3,5-8} Unfortunately, due to lack of time, resources, HCT awareness, and strong relationships between pediatric clinicians and their patient/parents, transfer to adult clinicians often occurs abruptly, frequently during times of critical illness, loss of health insurance, poor disease control, or other life transitions. In these cases, an unprepared young adult who lacks self-management skills is thrust into an adult model of care, where he or she may not receive still-needed support.

In 2011, a Clinical Report published by the AAP on HCT defined the fundamental components of successful transition, which were subsequently adapted into Six Core Elements™ of HCT, which are essential for all parties' success in the transition process.⁶ HCT, conceptualized with a patient-centered medical home in mind, is also essential to subspecialty care, as a majority of children with special health care needs survive into adulthood and need transition support in both primary as well as subspecialty care.⁸ Accordingly, many North American and European medical organizations have begun to outline recommendations for HCT specific to their population based on these elements. In various clinical settings, transition support can be assessed and enhanced through quality improvement methodology using Got Transition™'s Current Assessment of Health Care Transition Activities tool.⁹

In rheumatology, the American College of Rheumatology (ACR) formed the ACR Transition Workgroup, which in 2016 designed “Transition Toolkits” based on the Six Core Elements™ of HCT in order to provide adult and pediatric rheumatologists with HCT support. The European League Against Rheumatism (EULAR)/Paediatric Rheumatology European Society (PRES) has published guidelines for HCT in rheumatology.¹⁰ Multiple sites across the world have begun to carry out research on HCT in rheumatic diseases, in addition to establishing transition clinics and programs to better care for this vulnerable population.⁹⁻²⁰

In 2010, prior to the recent national and international HCT efforts, Chira *et al* surveyed the Childhood Arthritis and Rheumatology Research Alliance (CARRA) membership regarding practices, barriers, and opportunities for improvement in HCT.²¹ CARRA is a research network comprised of pediatric rheumatology physicians, allied health professionals, researchers, and

parents from the United States and Canada. The majority of practicing pediatric rheumatology clinicians from these countries are CARRA members. Since this 2010 survey was conducted, several guidelines and tools to improve HCT have been developed and widely disseminated in the rheumatology community, including the Six Core Elements™ of HCT and the ACR Transition Toolkit. We therefore conducted an updated survey to determine if changes have occurred in HCT perspectives, practices, and barriers among pediatric rheumatology healthcare providers in the US and Canada.

METHODS

Survey Development and Distribution. In January 2018, a subgroup of the CARRA Transition Workgroup began development of a survey of North American pediatric rheumatologists regarding HCT perspectives, practices, and barriers. Survey questions were adopted from the previous 2010 CARRA HCT survey, and additional questions were added pertaining to use of new transition tools and the development of transition-focused clinics. Questions assessed clinician and practice demographics, patient population, transition and transfer practices, transition resource utilization, transition barriers, and transition outcome measures. Got Transition's™ Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers was used to measure clinic-based transition processes on a scale of 1 (basic) to 4 (comprehensive). The Current Assessment is an objective scoring method that measures the implementation of transition processes corresponding with the Six Core Elements of Health Care Transition™: Transition Policy, Transition Tracking and Monitoring, Transition Readiness, Transition Planning, Transfer of Care and Transfer Completion.

Following development of the initial questionnaire, the survey was pilot tested, refined and approved by 13 members of the CARRA Transition Workgroup. The final survey included 25 items (Appendix 1) and was administered online via Survey Monkey®. In April 2018, CARRA members received a link to the online survey via email. At the time of survey distribution, CARRA included 396 survey-eligible members, defined as CARRA members who provide medical care to pediatric rheumatology patients. Informed consent was obtained for those completing the online survey. Institutional Review Board approval was obtained from the University of Utah prior to survey distribution (IRB #00110681).

Statistical analyses. Univariate statistics were used to describe the total sample, item responses, standard deviations, and distributions. Normal distribution of responses was confirmed using histograms. Bivariate analyses were conducted to compare individual item responses from the 2010 and 2018 surveys, including chi-square and two-tailed independent t-tests, as appropriate. All statistical analyses were conducted in IBM SPSS Statistics 25.²²

RESULTS

Over half (217/396) of eligible CARRA members completed the 2018 survey (Table 1). Participants included pediatric rheumatologists (74%), adult- and pediatric-trained rheumatologists (4%), pediatric rheumatology fellows (18%), and other (including emeritus faculty and advanced practice providers [4%]). Clinicians surveyed had an average of 5 to 10 years of experience caring for pediatric rheumatology patients. Most providers were associated

with university-affiliated practices (87%) based in the United States (91%), with a mean number of 5.9 (SD 2.9) attending rheumatologists and advanced practice providers per practice. Respondents reported caring for a significant number of adolescents aged 12-18 years (with a mode of 25-49% of providers' total patient population). They also care for a number of young adults between the ages of 19 and 25 (6-10%).

The most common target age range to begin transition planning remains 15-17 (49%, Figure 1). However, from 2010 to 2018 there was a significant increase in the percentage of providers starting planning at ages 12-14 (from only 27% in 2010 to 42% in 2018, $p<0.05$) and a significant decrease in the providers who begin transition planning between 18 and 20 (from 26% in 2010 to only 5% in 2018, $p<0.05$). As depicted in Figure 2, in 2018 fewer clinicians stated that their aim was to transfer patients to the care of adult rheumatologists after 21 (13% in 2018 compared to 32% in 2010, $p<0.05$), and more providers found they were transferring patients between the ages of 19 and 20 (63% in 2018, compared to 52% in 2010, $p<0.05$). In addition, Canadian providers had 16.5 times the odds of transferring patients prior to age 21, compared to providers from the U.S. (data not shown, $p<0.001$). Other provider demographics were not associated with age of transition planning or age of transfer.

While 31% reported using the recently-created ACR transition tools to support HCT in their clinical work, 63% of respondents did not consistently address HCT with their patients (data not shown). Only 17% of those surveyed have an official transition policy in place for their clinic; however, this did represent an increase from 8% in 2010 (data not shown, $p<0.01$). Approximately one-quarter of respondents reported having a dedicated transition clinic at their institution where patients can be seen by both pediatric and adult rheumatology clinicians. A majority of providers indicated that they do not require patients age 18 and older to sign a consent form in order to allow parents to participate in the visit and receive health care information. While 92% of Canadian providers routinely ask parents leave the room for at least part of the visit before patients reach the age of 18, only 41% of U.S. respondents do so (data not shown).

Across all six items in the Current Assessment of Health Care Transition query, the mean score was less than 2, with a score of 1 representing basic HCT support and 4 representing comprehensive HCT support (Figure 3). When asked which outcomes should be used to define successful transition, the most common responses were an adult rheumatology visit within 6 months of the last pediatric visit (80%), adherence to medications and plan of care (78%), continuous insurance coverage (78%), and continuous access to care (76%). These are similar to international HCT outcome metrics.²³

When compared to the 2010 survey, three of twelve transition barriers significantly decreased (Figure 4): (1) availability of adult primary care providers (24% vs 8%, $p<0.001$), (2) availability of adult rheumatologists (26% vs 14%, $p<0.001$), and (3) transition knowledge and skills of pediatric staff (26% vs 14%, $p<0.001$). However, in 2018 more clinicians reported the close bond among adolescents, parents and pediatric providers as a barrier to transition, compared to the 2010 survey (55% vs. 32%, $p<0.001$ Figure 4). Ninety-five percent of providers identified adolescents' lack of knowledge and advocacy skills as a barrier.

DISCUSSION

This study describes the perspectives and practices of North American pediatric rheumatology providers as they transition their patients from pediatric to adult rheumatology care, providing an updated picture from the 2010 CARRA HCT survey. While most clinicians aim to transfer patients to adult rheumatology care between the ages of 18 and 21, they self-report that the actual age of transfer is more often age 21 or older. Most pediatric rheumatology providers in this survey stated they aim to begin transition preparation between the ages of 12 and 17.

When compared to the 2010 survey, both the planned age of transfer and the estimated age at time of transfer were notably younger in the 2018 survey. While the average age at transfer may be decreasing, data suggests that many pediatric specialists still continue to care for patients with childhood-onset conditions well into adulthood. Pediatric subspecialists in other fields report caring for patients into their mid-20s or 30s in pediatric clinics.^{24,25} Providers who practice at free-standing children's hospitals and have been in practice longer have been shown to be more likely to care for patients into adulthood.²⁶

Age is not the only factor that acts as a catalyst for the transfer to adult care. Perceived readiness for an adult model of care, as well as life milestones such as graduation or marriage, may all prompt transfer.^{24, 25, 27, 28} Pediatric subspecialists across many fields report transferring patients when they become pregnant, develop adult co-morbidities, or are found to abuse illicit substances or alcohol, which sometimes leads to precipitous transfer of patients who have not yet achieved readiness.²⁹ In contrast, clinicians may be hesitant to transfer patients with ongoing active disease, upcoming planned procedures, or end-stage disease.^{26, 30, 31}

While nearly one-quarter of pediatric rheumatology clinicians in our survey reported having a dedicated transition clinic at their institution, many cited the lack of available adult rheumatology providers as a barrier to HCT. In theory, transition clinics should facilitate transfer to adult care; however, pediatric cardiologists at sites with adult congenital heart programs still cite a lack of qualified adult providers as a barrier to HCT (24). While improved in this study, the perceived lack of adequately-trained adult specialists available to care for young adults with childhood-onset conditions is also reported by pediatric cardiologists, orthopedists, urologists, endocrinologists, neurologists, oncologists, and hematologists, although qualified specialists often exist.^{26, 27, 35-40}

Contributing to this perception of insufficient qualified adult subspecialty clinicians may be the fact that a majority of adult providers report being uncomfortable taking care of patients with medically complex pediatric-onset conditions, including those with childhood-onset rheumatic diseases.^{41, 42} Encouragingly, North American pediatric rheumatology providers in our survey perceived improved availability of adult rheumatologists willing to care for their patients in 2018 as compared to 2010.

Similar responses were seen in both the 2010 and 2018 CARRA surveys patient and parent attachment to their pediatric clinician is perceived as a major barrier to HCT. This is a trend

seen across most pediatric subspecialties.^{24-27, 30, 31, 35, 37, 40, 43} It is unclear why this barrier was seen as more prohibitive in the 2018 survey comparatively. In addition to the provider's relationship with the patient, adolescent knowledge and advocacy skills continue to be a barrier, echoed in findings from other chronic diseases like type 1 diabetes mellitus, inflammatory bowel disease, and various cancers. In a review of HCT in those with sickle cell disease, transition was further complicated by neurocognitive impacts of the disease, as well as sociodemographic factors and health care disparities.⁴⁴ These factors likely also affect pediatric rheumatology patients, especially those with systemic lupus erythematosus.⁴⁵

Our findings suggest overall increased awareness of HCT concepts and processes among rheumatology clinicians, as evidenced by more providers beginning transition planning by age 14 and by a notable decrease in the number of providers experiencing three barriers to transition care. We hypothesize that improved awareness of HCT by pediatric rheumatology staff, which was lower than prior investigation, could play a key role in the improving the transition process. However, lack of time and reimbursement for transition planning and transfer remained significant barriers to HCT in the 2018 survey. In addition, a lack of medical records available to both the young adult and the adult clinician, as well as a lapse of care during the time between seeing the pediatric and the adult rheumatologist, may impact patients' health and healthcare during the transition to adult rheumatology.⁴² Successful integration of transitioning young adult patients into adult rheumatology practices requires transition skills and knowledge, but also infrastructure, time, and resources, luxuries many adult rheumatologists, in private or academic practice, do not have.^{42, 45} It is encouraging that our study suggests inroads are being made towards overcoming certain barriers, but clearly there are additional obstacles to surmount.

In spite of trends towards increased awareness of the need for structured transition processes to improve care, the 2018 study found less than half of North American pediatric rheumatology clinics have these processes in place. The Six Core Elements™ of HCT illustrated in Figure 3 all have means less than 2 (range 1-4). While these metrics could be skewed by the averaging of very high performing programs with very low, the transition policy element is congruent with the reported 17%, gathered in separate a survey question. These findings are consistent with other pediatric subspecialties, which report implementation of transition assessments and protocols in only 50% of practices, even when providers have been trained in transition processes.^{24-26, 30, 38, 39} For example, providing a medical summary and contacting adult clinicians are recommended as part of Got Transition™'s Six Core Elements of HCT, but these are performed inconsistently across pediatric subspecialties, resulting in minimal adult provider involvement in the transition process.^{30, 37-39} Almost all queries of pediatric subspecialists have articulated a need for additional institutional resources for transition education and process improvement implementation.

Our findings are in line with transition surveys of other pediatric subspecialties, including pediatric inflammatory bowel disease (IBD) providers which also saw a wide range of practice patterns, including the target age at which to begin transition planning and the target age at which to transfer.⁴⁶ In line with the 17% of pediatric rheumatology providers who indicated using a formal transition policy, 14.2% of respondents to the IBD survey reported having a formal transition policy. Also similar to our findings, the IBD survey identified many barriers to transition, with 99.3% of providers identifying at least one barrier.

Notably, Got Transition™ recently launched the third iteration of their website and tools, which now includes additional templates and easy-to-implement materials.⁴⁷ As an example, the website provides a sample transition policy, which can be used in full or adapted to fit the specific needs of a subspecialty, institution, or individual clinical site. In addition, the 2021 Pediatric Rheumatology Symposium (PRYSM) will feature a session on transition in an effort to assist with dissemination and uptake of Got Transition™ tools and other transition best practices.⁴⁸ More training opportunities are needed, especially workshops which provide active learning opportunities for providers and clinical support staff to practice key transition skills.⁴⁹

This study has some notable limitations. First, this study had a response rate of 55%, creating opportunity for bias, as individuals who are not interested in or familiar with HCT may have been less likely to respond to the survey. In addition, CARRA membership includes both American and Canadian pediatric rheumatology providers, though the majority of our respondents were based in the U.S. Given significant structural differences in health care systems between these two countries, there may be differences in HCT experiences and practices between the two groups; however, we were not able to explore these differences due to the small number of Canadian respondents. Finally, this survey relies on self-reported data; practice patterns and patient ages therefore represent provider estimates rather than actual measurement and are therefore subject to possible recall bias.

CONCLUSION

Healthcare transition is an important and challenging process in pediatric rheumatology. This survey of pediatric rheumatology clinicians demonstrates some improvement in HCT knowledge, barriers, and processes as compared to data from 2010. However, most practices still provide minimal support for HCT, and tools created to promote a structured HCT implementation are being adopted slowly. Further research is needed to understand how to efficiently and effectively facilitate the planning, transfer, and integration into adult care for young adults with childhood-onset rheumatic diseases, with the need to support providers and practices in the process creating structures to promote best practices in the care of adolescent and young adult rheumatology patients.

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Table 1. Characteristics of CARRA Pediatric Rheumatology Provider Transition Survey

Respondents

Figure 1. Target Age to Begin Transition Planning in Pediatric Rheumatology Clinics, 2010 and 2018

Figure 2. Target Age and Actual Age of Transfer from Pediatric to Adult Rheumatology Care, 2010 and 2018

Figure 3. Pediatric Rheumatologists' Report of their Current Assessment of Healthcare Transition Activities, 2018

Figure 4. Barriers to Health Care Transition Reported by Pediatric Rheumatology Providers, 2010 and 2018

APPENDIX:

Appendix 1: CARRA Survey

Accepted Article

**Childhood Arthritis Rheumatology Research Alliance (CARRA) Survey
Respondent Characteristics**

	2010	2018
Total CARRA members participating	158 (55%)	202 (55%)
Country		
United States	140 (89%)	189 (89%)
Canada	18 (12%)	13 (6%)
Position		
Pediatric Rheumatologist	127 (80%)	150 (74%)
Adult/Pediatric Rheumatologist	8 (5%)	9 (5%)
Fellow	23 (15%)	38 (19%)
Other	—	5 (2%)
Years in Practice		
< 5 years	27 (17%)	62 (31%)
5 - 10 years	78 (49%)	50 (25%)
11 - 15 years	38 (24%)	30 (15%)
> 15 years	13 (8%)	58 (29%)
Number of rheumatologists and mid-level providers in practice		
1	11 (7%)	18 (9%)
2	40 (25%)	20 (10%)
3	30 (19%)	15 (7%)
4	21 (13%)	21 (11%)
>5	56 (36%)	128 (63%)
Practice type		
University affiliated	140 (89%)	181 (89%)
Private practice	8 (5%)	10 (5%)
Other	10 (6%)	11(6%)
Proportion of patients age 12 - 18 years seen weekly		
0% - 24%	16 (10%)	23 (11%)
25% - 49%	78 (49%)	89 (44%)
50% - 74%	54 (34%)	87 (43%)
75% - 100%	10 (6%)	3 (2%)
Proportion of patients age > 19 years seen weekly		
0%	27 (17%)	22 (11%)
1% - 5%	78 (49%)	103 (51%)
6% - 10%	37 (23%)	49 (24%)
>11%	16 (10%)	28 (14%)

Figure 1. Target Age to Begin Transition Planning in Pediatric Rheumatology Clinics, 2010 and 2018

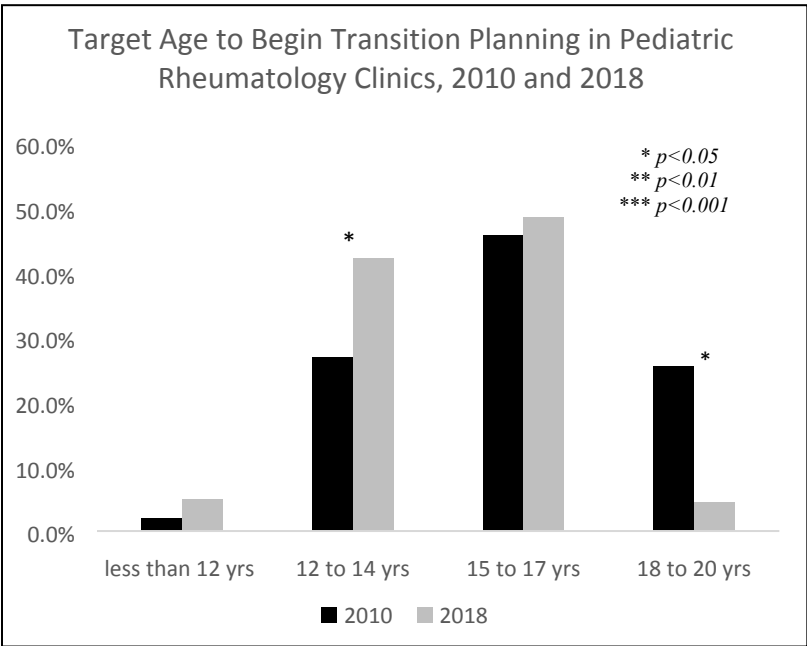


Figure 2. Target Age and Actual Age of Transfer from Pediatric to Adult Rheumatology Care, 2010 and 2018

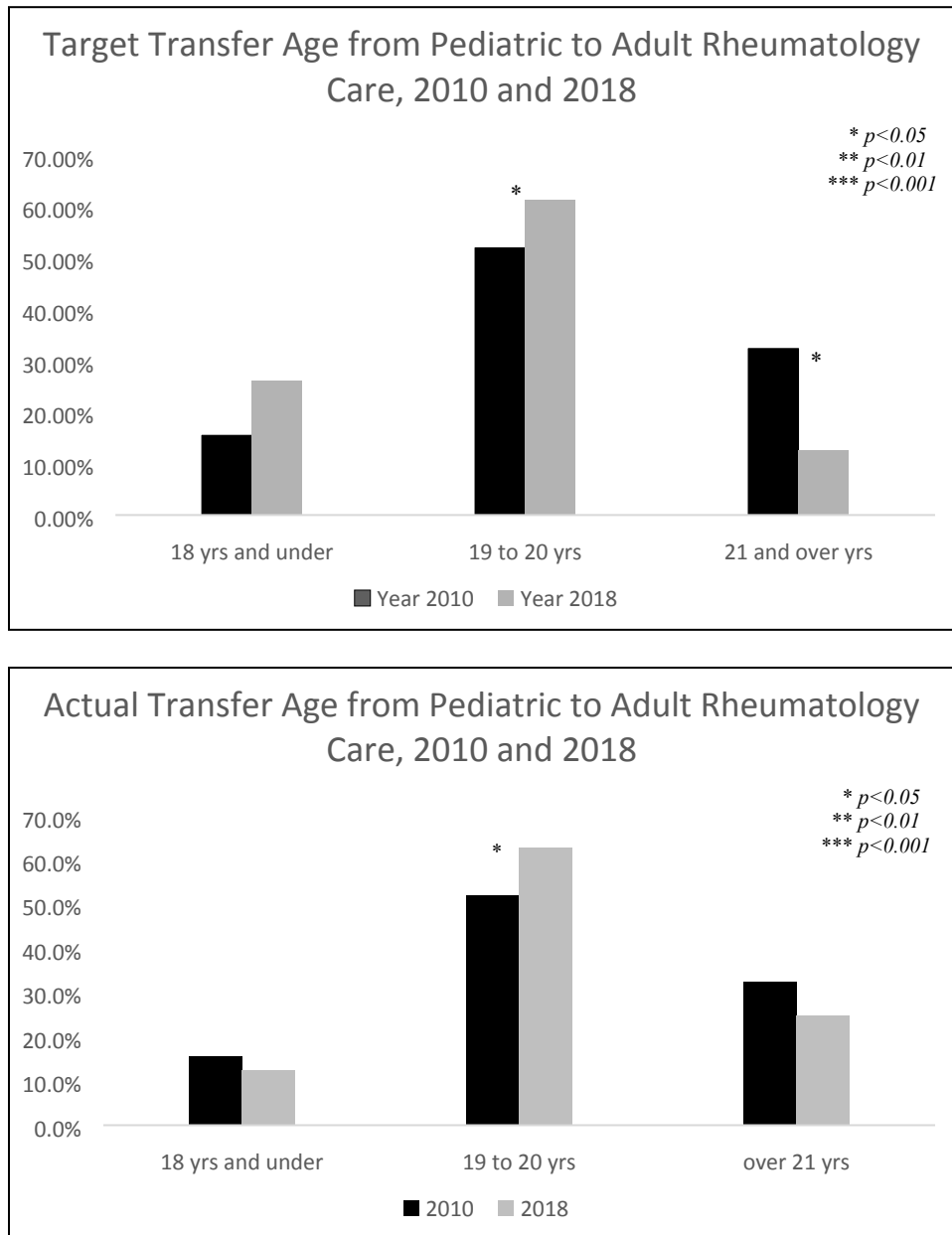


Figure 3. Current Assessment of Healthcare Transition Activities among Pediatric Rheumatology Providers, 2018

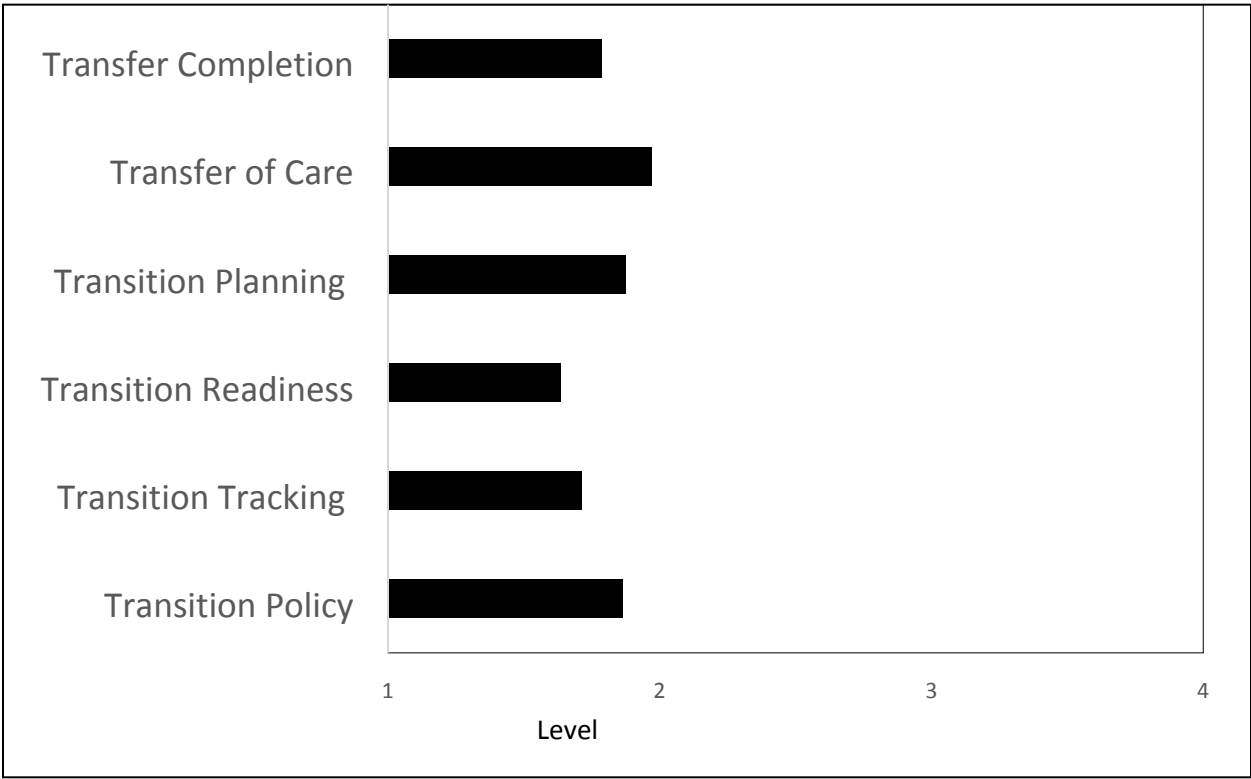


Figure 4. Barriers to Health Care Transition Reported by Pediatric Rheumatology Providers, 2010 and 2018

