

## QOL 32

### Satisfaction with Teen Transition Services at US Hemophilia Treatment Centers by Center – Variation by Pediatric and Lifespan Centers 2014 and 2017

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#### Submission Group

Quality of Life/Outcomes Research

#### Abstract

**Background:** Helping teens with bleeding disorders prepare to manage their care as they transition to adulthood is a national priority for US Hemophilia Treatment Centers (HTC). The National HTC Patient Satisfaction Surveys (PSS) reveal high satisfaction with HTC teen transition services. Yet how satisfaction differs comparing HTCs that primarily care for children to HTCs that care for patients throughout the lifespan is unknown. **Objective:** To assess variation in patient satisfaction with US HTC teen transition services by HTC type. **Methods:** The US HTC Network conducted nationally uniform patient satisfaction surveys in 2015 and 2018 on care received, respectively, in 2014 and 2017. A Regional workgroup devised, piloted, and finalized an electronic, two-page survey for self-administration at clinic, or at home, in English or Spanish. Participation was voluntary. Respondents were anonymous but identified their HTC. Parents completed surveys for children under age 18. The PSS included two teen transition questions for respondents age 12-17 to complete. HTC type was categorized as 'pediatric' if >80% of responses were from patients/caregivers of individuals under age 18, and 'adult' if >80% were from patients over age 24. All other HTCs were categorized as 'lifespan'. For both years, approximately 26% of HTCs were classified as pediatric, 52% as life-span, and 22% as adult. **Results:** Over 700 teens age 12-17 (or their parents/guardians) from an average of 130 HTCs (94.0%) from all US regions participated in 2015 and 2018. Approximately 96.5% of teens at pediatric HTCs (96.4% - 96.5%) and 96.2% at lifespan HTCs (95.9% - 96.5%) reported being 'always' or 'usually' (A/U) satisfied with HTC services overall. On average, 90.4% of teens at pediatric HTCs (90.1% - 90.7%) and 91.0% at lifespan HTCs (90.3%–91.6%) reported being A/U satisfied with how HTC clinic staff talked about how to care for the bleeding disorder as they became an adult. Similarly, 92.5% (92.0%– 92.9%) of teens at pediatric HTCs and 92.5% (92.3%-92.7%) reported being A/U satisfied with how the HTC clinic staff encouraged them to become more independent in managing their bleeding disorder. **Conclusions:** HTC patients age 12-17 years consistently report very high levels of satisfaction with HTC teen transition services, regardless if the HTC primarily cares for patients up to age 17, or throughout the life-span. This suggests teens receive support and tools to successfully transition to adult care across the US HTC Network. A national uniform HTC Patient Satisfaction Survey provides vital information, is feasible to conduct using a regional structure, and well received nationwide.