OPEN

A Quality Improvement Approach to Ensuring Access to Specialty Care for Pediatric Patients

Sheetal S. Vora, MD, MSc*; Talia L. Buitrago-Mogollon, MHA, CPHQ†; Sarah C. Mabus, MLA†

Introduction: With pediatric rheumatologists in short supply, maximizing appointment availability and streamlining primary/specialty collaboration are essential. Lack of an efficient referral process impacts outcomes, quality of life, satisfaction, affordability, and resource allocation. Before this quality improvement project, our clinic had a 3- to 5-month backlog for new referrals. **Methods:** Using the model for improvement with numerous rapid-cycle plan-do-study-act cycles, this team restructured processes, developed a triage tool for communication across the care continuum, maximized staff roles in multiple areas, and instituted cross-disciplinary communication strategies to reduce appointment delays while significantly increasing efficiency. **Results:** The team succeeded in decreasing time from referral to specialty consult by 60%, decreasing no-show rates from 15% to 6%, and increasing throughput by an average of 45 more patients per month. Most new patients can now see our specialists within 23 days, meaning the children in our community have 65% shorter wait times for rheumatology services. **Conclusion:** The use of a triage algorithm with structured communication allows multidisciplinary care teams at both the referring and receiving providers to efficiently and accurately place patients into specialty care. This highly scalable and transferable project was accomplished with no direct financial outlay yet yielded significant returns by standardizing processes, empowering the entire care team to build skills, and improving communication. *(Pediatr Qual Saf 2022;7:e566; doi: 10.1097/pq9.0000000000000566; Published online June 14, 2022.)*

INTRODUCTION

Problem Description

Early diagnosis for rheumatic conditions is crucial for the best functional outcomes. As illustrated by Greenwood-Lee et al., there are four primary barriers to efficient primary/specialty interactions: (1) lack of clinical decision support such as triage and referral algorithms; (2) lack of information management support such as outdated and unconnected communication systems allowing patients to fall through cracks and referral loops; (3) faulty process for patient flow

From the *Department of Pediatrics, Atrium Health Levine Children's, Charlotte, N. C.; and †Center for Advancing Pediatric Excellence, Atrium Health Levine Children's, Charlotte, N. C.

*Corresponding author. Address: Sheetal S. Vora, MD, MSc, Division of Rheumatology, Atrium Health Levine Children's, 1000 Blythe Boulevard, Charlotte, North Carolina 28203
PH: 704-381-2273
Email: sheetal.vora@atriumhealth.org

between primary/specialty care plus supply and demand management; and (4) lack of monitoring for care quality such as insufficient data tracking and ongoing improvement.[1]

The difficulty of identifying rheumatic disease symptoms, which can result in misdiagnosis,[2–5] combined with the high volume of referrals and shortage of pediatric rheumatologists, hinders access for many children. There are currently about 300,000 US children diagnosed with juvenile idiopathic arthritis (JIA).[6] Six states have only one pediatric rheumatologist while nine states have none; the average JIA patient travels 50+ miles to receive care.[6] Foster et al.[7] found a median care delay of 20 weeks, with many children referred to multiple specialties and subjected to multiple inappropriate invasive procedures. Pediatric lupus patients can have care delays for over a year.[8]

In 2016, the rheumatology clinic at Atrium Health's Levine Children's Specialty Center (LCSC) had a 3- to 5-month backlog for new appointments due to clinic capacity. Some referred patients who were never seen in an outpatient clinic experienced a range of negative consequences including intensive care unit admission, rehabilitation, a complicated combination of multispecialty care, and permanent disability. High patient demand, lack of an efficient process, and limited provider staffing adversely impacted outcomes and resource allocation. These heartbreaking and high-cost events might be avoided with appropriate and timely rheumatology care.

This QI project aimed to improve the timeliness of consult appointments by reducing the number of days from referral for rheumatology consult to scheduled appointment from an average of 65 business days (BDs) to an average of 30 BDs by December 31, 2019.

METHODS

Context

The rheumatology clinic was one of eight specialties in LCSC in 2017. LCSC Rheumatology was founded in 2011 with one board-certified pediatric rheumatologist with time divided between clinical and academic duties, adding a second position with divided time in 2012. Before this, most patients traveled to an academic center 250 miles away. To meet demand, LCSC Rheumatology expanded to two additional sites—one in a densely populated nearby area, and one in a rural region 60 miles north.

Due to the project's aim to improve the quality of care locally, the Institutional Review Board approved the project as a Quality Improvement Project.

Intervention

This project used the Model for Improvement with rapid PDSA (plan, do, study, act) cycles. The team completed a Failure Mode and Effect Analysis to identify facilitators and barriers to the current referral process. It surveyed the multidisciplinary team and patients/families to identify the most common and impactful failures. Results informed a key driver diagram (Fig. 1) highlighting lack of a standardized referral and triage process, lack of available appointments for higher acuity patients, limitations in referral coordinators' and families' ability to contact them, and lack of empowerment for frontline personnel to aid with triage. Table 1 summarizes numerous interventions, with key changes discussed below.

Because lack of a consistent referral/triage process was the primary barrier, the two rheumatologists reached consensus on the most common clinical characteristics indicating rheumatic disease requiring ongoing care, and cross-referenced this list against actual referrals. Using this knowledge, the team created decision-support tools to standardize triage (receiver, Fig. 2A) and referral (sender, Fig. 3) tools. A triage tool provides four acuity-based categories for appointment timeframes, allowing the entire team from providers to referral coordinators to participate in triage. The referral tool, completed by primary care providers, educates them about significant symptoms and informs them which laboratories should be completed and sent with the tool for higher triage placement.

Team communication focused on the timely re-evaluation of referral data and feedback on tool completion and application during huddles, which allowed for multiple iterations of the processes. Streamlined communication between the specialty team and families was addressed next. Families returning missed calls from the clinic are routed to an answering service that covers all LCSC specialties. The new process requires coordinators to include the expected appointment timeframe in the electronic medical record (EMR). This helps the answering service appropriately schedule in real time when patients call back, rather than asking families to leave a message for the rheumatology practice to call them back.

Both rheumatologists redesigned visit templates to accommodate two new appointment slots to alleviate appointment availability limitations, resulting in four weekly appointments reserved for high acuity patients. Although this improved referral coordinators' ability to follow the triage process, it was insufficient. Providers used "urgent held" and "follow-up" slots to meet demand.

Primary care providers' ability to book appointments directly also impacted availability, often claiming urgent slots for nonurgent patients. Direct booking capacity was removed in mid-December 2017, thus driving all referrals through the triage process.

By March 2018, average provider visits per month increased by 13 (physician champion) and by 15 (division chair), covered by a total of 1.5 clinical full-time equivalent. The subsequent addition of a third part-time provider in October 2018 helped to balance supply and demand. It allowed the physician champion to revert to her normally contracted clinical time (thus total coverage of 2.0 full-time equivalents combined across three providers).

Training required multiple approaches for internal staff and external stakeholders. Internal training focused on understanding data collection, practicing the new triage protocol, and using communication tools to facilitate feedback. The physician champion and referral coordinators independently triaged patients, then compared and discussed their decisions. Initially held weekly, these meetings were reduced to bi-weekly and ultimately to monthly owing to increasing coordinator independence and confirmed accuracy. As a result of these meetings, we created the joint pain algorithm (Fig. 2B).

External training focused on the new triage criteria and protocol. Training sessions included multiple visits to three large networks' primary care practices. Training materials included a video shared with all practices demonstrating the use of the provider referral tool. We found the material was most effective when reinforced with in-person education.

Study of the Interventions: We evaluated each measure with run charts and later Statistical Process Control Charts (SPC) following specific probability rules and statistical methods, to assess interventions' impact. Standard SPC chart rules were used to determine centerline shifts.[9] All charts were created with QI Macros Software Package Plugin for Excel.

Measures/Outcomes: We measured two outcomes: (1) reduction of average time from referral to consult for
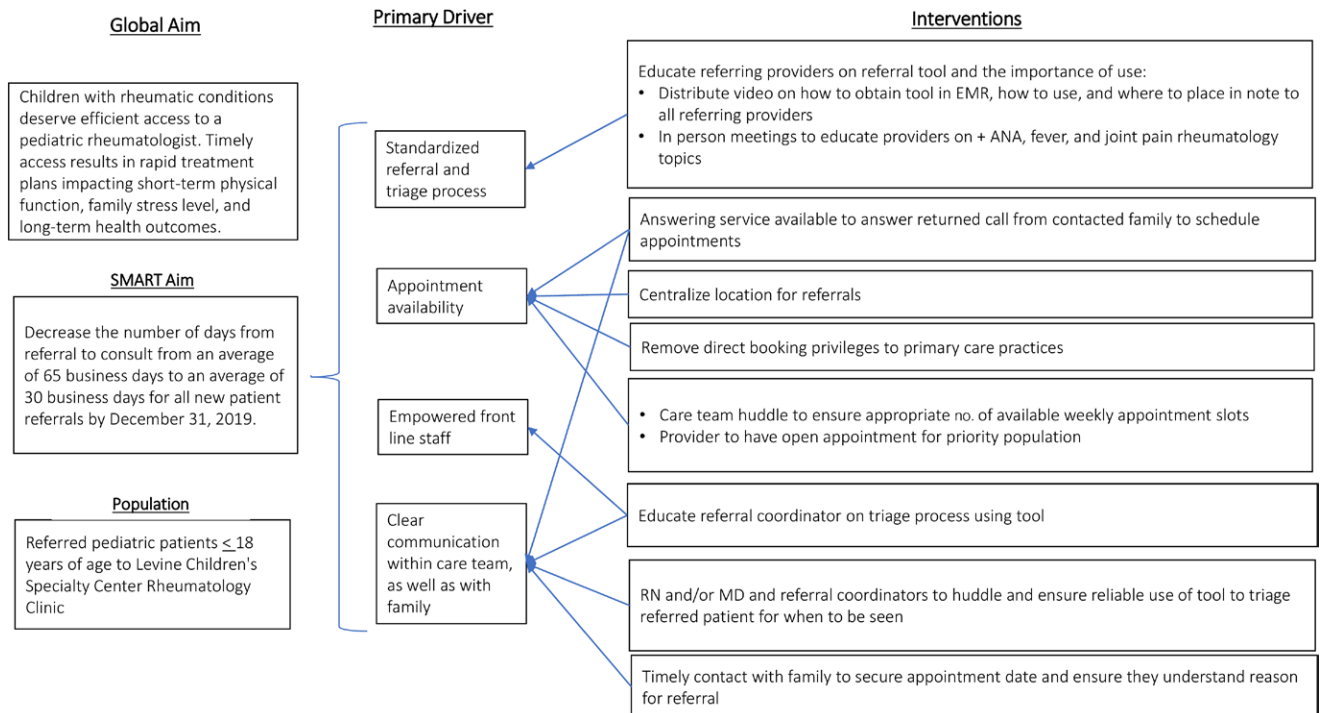
Fig. 1. Key driver diagram project road map. It facilitated the team's visualization of the aim, drivers, and interventions guiding progress for those priority rheumatology referrals, identified by triage tool, who required an appointment within 30 BDs.

all new referrals and (2) whether the priority population was seen within 30 BD. The team defines priority population as patients requiring ongoing rheumatology care, that is, pediatric patients younger than 18 years of age referred from another provider and requiring the expertise of a pediatric rheumatologist for care of a perceived rheumatic/autoimmune condition with symptoms to include any of the following criteria: antinuclear antibody titer >1:320, specific joint swelling or pain, persistent fever, or rash.

These two items were tracked initially in Microsoft Excel and later moved to a Redcap database.[10,11] Weekly team huddles reviewed data and ensured all patients were entered accurately and reliably.

Process measures included reliability of the triage tool and referral tool use by referring physicians. The weekly 30-minute huddle allowed the full team to review data and talk through global issues. In the first 6 months, the lead physician and referral coordinators also met weekly for an hour to compare the triage level assigned by the coordinator (via the tool) versus the physician score for each patient. These were difficult discussions early on, and the physician worked to develop open, trusting relationships with staff to facilitate dialogue and maintain a collaborative environment. Other successful tactics included focusing on the process rather than the individual and using data to drive decisions.

Although specific balancing measures were not established, no-show rates and patient volumes were later provided monthly by LCSC's administration.

After process changes were tested, the team conducted informal surveys asking parents questions about their experience with the referral process and timeline, specifically how soon they received a call, whether they considered going somewhere else, and what could have been done better.

RESULTS

The measure of decreasing time from referral to consult from 65 to 30 BD was achieved in August 2018. Figure 4 shows several signals of special cause variation. The mean (centerline) shifted three times, ultimately landing at 23.7 BD, a 65% decrease in days a new patient waits for an appointment.

The goal of increasing the rate of priority population seen within 30 BD from 39% to 85% was achieved in December 2017 and has been sustained.

The reliability of the initial triage tool to identify acuity compared to the final diagnosis by providers was 60%. PDSA cycles resulted in 5% improvement with special cause starting July 2018. Although the team hoped for a higher increase, this highlights the difficulty of diagnosing a rheumatic condition. The rate of referral tool use was also evaluated monthly, and reached a final mean use rate of 37%.

The preproject no-show rate was a median of 9% (January 2017); by project conclusion, it dropped and sustained at 6% (December 2019). This continues to be the lowest no-show rate at LCSC.

Table 1. Intervention Timeline

Date	Intervention(s)
August–December 2016	Baseline data collection
October 2016	Team meetings started
	Evaluated all referrals and divided them into 3 categories: those needing ongoing rheumatic care, one-time visit, and not needing rheumatology
	Further investigated categories to find combinations of laboratories and symptoms to better understand those that ended in different acuity levels
June–August 2017	Creation of 4-level triage tool based on clinical characteristics with 6 most frequent referring complaints matched with content expertise resulting in those needing ongoing rheumatic care and one-time visits
July 2017	Referral tool introduced to referring providers via both paper and EMR
August 2017	Introduction of triage tool to referral coordinator
	Weekly check-in starts between MD and referral coordinator for reliability and validation of triage system
	Switch to single central fax machine used to receive all paper referrals
September 2017	Referral tool introduced to providers within our health system at system-wide meeting
October 2017	Referral tool in-person workshop for single internal practice
November 2017	Iterations of triage tool revised and implemented
December 2017	Direct booking appointments closed
January 2018	Created an education video for providers on referral tool use
	Rheumatology nurses become referral coordinator point of contact for challenging referrals for triage and verification of triage appropriateness
	Nurses evaluate provider schedules to determine adequate appointment availability and communicate with referral coordinators
	Specialty center answering services educated on process to schedule patients based on referral coordinator triage
February 2018	2 slots held/created on providers' schedule to accommodate urgent triage referrals
February–April 2018	Referral tool introduced to 2 large outside referring hospital systems' provider leaders and office managers
March 2018	Triage tool revision and completed education video sent via email to all referring providers
April 2018	Outside Office coordinator teach back on referral tool use
May 2018	Monthly MD or RN verification of triage appropriateness with referral coordinator
September 2018	Second presentation of referral tool and survey of providers for facilitators and barriers to use of referral tool
October 2018	Hypermobility symptoms and unique triage category added to triage tool
	New provider joins rheumatology practice
September 2019	Third presentation of referral tool and survey of providers for facilitators and barriers to use of referral tool
October 2019	Referral tool formally introduced at provider meeting for one outside hospital
	Start of collaborative clinic for a specific patient population identified via triage tool
December 2019	Instructional video created for outside referring providers to access referral tool in EMR

Patient volume increased from a mean of 190 in 2016 to a mean of 235 with signals of special cause starting July 2017 through February 2018 (Fig. 5). Since data for the subsequent two months dipped, the team waited to shift the mean (centerline) until the next signal of special cause variation in May 2018. This volume shift represents an average of 45 more patients per month (May 2018–December 2019). We did not observe additional improvement because physicians' schedules were at capacity.

DISCUSSION

This project surpassed its initial aim to decrease the number of days from referral to consult from an average of 65 BD to an average of 30 BD for all new patient referrals by December 31, 2019, ultimately achieving an average of 23 BD. In addition to improving wait times seven months before adding a third provider, this project also showed improvement in the number of patients seen and no-show rates. It demonstrated how structured communication accompanied by a triage algorithm can support multidisciplinary care teams at both the referring and receiving providers to place patients efficiently and accurately into specialty care.

Interpretation
A more strategic approach to triage and engaging referral coordinators in the triage process were the most effective interventions. Incorporating decision-support helps the primary care team understand all referral requirements, while the comprehensive summary helps the receiving team correctly assess acuity and scheduling. Outcome measure performance has been sustained even when other interventions fluctuate in reliability. We are currently spreading these two interventions to several other LCSC specialties seeking similar benefits such as improved access, volume, and no-show rates.

The triage tool facilitated decision-making for nonclinical care team members, allowing them to correctly assess acuity and independently assign timeframes without having rheumatologic expertise. As referral coordinators found their decisions concurring with physician assessments, they developed increasing confidence thus freeing nurses and physicians for more critical work. The use of the referral tool was the most difficult aspect to influence. Currently, there is only 37% compliance. True reliability hinges on tool completion: if the primary care provider does not complete the referral tool correctly, the receiving clinic is limited in their ability to place patients correctly. In addition to the different behaviors, processes, and environments of referring providers, many providers belong to different health systems, and some are independent providers with no EMR access. A provider survey identified a barrier to completing the referral tool as "forgetting it exists" due to the rarity of rheumatologic conditions. The next steps will focus

on incorporating more EMR automation from referring systems, including a hard stop if the tool is not completed. Incorporating stakeholders from referring clinics in the tool design likely would have increased buy-in and improved use, and may have an impacted tool structure and user understanding. Future work should consider including referring stakeholders in process design, specifically influencing tool use by identifying physician champions who care for children with rheumatic symptoms in their practice.

Another challenge has been maintaining consistent answering service training. That department experienced vast turnover, and including the process in their training has been difficult due to a separate reporting structure.

The group reports enhanced teamwork and communication because of this project and the culture of safety

---

A Rheumatology Triage → Book with any available rheumatologist

Bucket **1**→ seen within 10 BDs of referral

> 4 out of 4 criteria need to be met:
> - o ANA titer $\geq$ 1:320
> - o Joint swelling [localized (right /left/ both) and specific (knee, etc.) identified]
> - o Fever
> - o Rash and/or Raynaud's
> - o Referral from another "specialist" and meets above 4 of 4 criteria

Bucket **2**→ seen within 17 BDs of referral

> 2 out of 4 criteria need to be met:
> - o ANA titer $\geq$ 1:320
> - o Joint swelling [localized (right /left/ both) and specific (knee, finger, toe etc.) identified]
> - o Rash and/or Raynaud's
> - o Uveitis requiring immediate additional medication treatment
> - o Referral from another "specialist" and meets above 2 of 4 criteria

Bucket **3**→ seen within 30 BDs of referral

> Meets 1 out of 9 criteria

> *****Look at Joint Pain Flow Diagram*****
> **(Figure 2B)**

- o ANA $\geq$1:640
- o Joint pain (specific location (knee, etc.) and localized (left/right) identified); and look at **Joint Pain Flow Diagram**
- o If one or more joint (NO swelling) or bilateral/multiple joint pain stated, must still be joint specific with side and accompanied by abnormal laboratory tests (+ HLA B27 or moderately elevated ESR $\geq$30 or CRP $\geq$ 2) *Note-> value should be elevated based on range of laboratory used**
- o Joint swelling [specific joint (knee, toe, finger etc.)]
- o Raynaud's
- o Uveitis currently under adequate treatment
- o Post hospital discharge follow-up
- o Pre-existing rheumatic diagnosis made by a rheumatologist or immunologist
- o > 3 months back pain with positive x-ray findings of sacroiliac (tail bone) involvement

Bucket **4**→ Does not have to be within 30 BDs

- o All other referrals regardless of clinical signs and symptoms
- o Recurrent fever
- o Multiple joint pain, not specific and not accompanied by abnormal labs

Bucket **H** (Hypermobility/Joint pain)→ Does not have to be within 30 BDs

- o If one (NO SWELLING) or multiple ($\geq$2 joints) joint pain (+/- Intermittent swelling) stated, must still be joint specific and accompanied by at least **1** Hypermobility symptom(s): headache, abdominal pain, anxiety/depression/ADHD, poor sleep, dizzy/faint/syncope, low Systolic Blood Pressure, rash (ONLY including hives/blotchy skin/Raynaud's/increased bruising).

Fig. 2. Triage tool algorithm for use by pediatric rheumatology receiving clinic. A, Decision support to aid with scheduling priority. B, Joint pain flow diagram—page two of triage tool. ANA, antinuclear antibody; CRP, C-reactive protein; ESR, erythrocyte sedimentation rate; HLA, human leukocyte antigen.
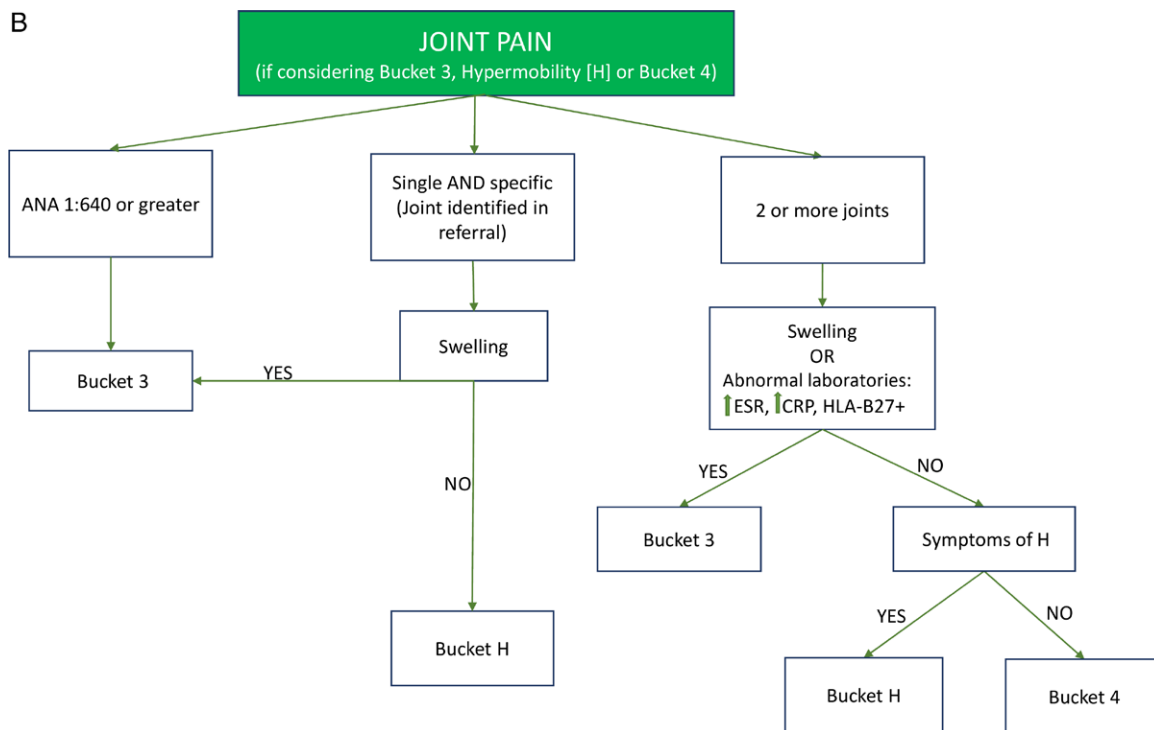
B

Fig. 2. (*Continued*).

it fostered. Providers and nurses report a reduction in hierarchies across staff and disciplines. Weekly meetings, including referral coordinators and physician champions led coordinators to feel acknowledged, validated, safe to discuss decisions, and empowered in their new ability to triage and competently offer families appropriately timed

Joint Pain	Unexplained Fever Lasting >10 Days	Positive Anti-Nuclear Antibody (ANA)

o Y or N→ ___Morning stiffness >15 minutes
o Duration of joint pain ___# weeks
o Y or N→ ___Dizziness/Fainting episodes/Syncope
o Y or N→ ___Low Systolic Blood Pressure for age/gender and height/weight
o Y or N→ ___Bruising/Hives
o Y or N→ ___Abdominal pain
o Y or N→ ___Anxious/Depressed/ADHD
o Y or N→ ___Poor sleep hygiene
o Are any affected joints: Answer Yes or No
o Y or N→ ___Swollen
o Y or N→ ___Red
o Y or N→ ___Fever >10 days
o Please indicate specific joints affected (include all that apply):
 Circle if L (left) or R (right) or Bilateral (B)
  o L or R or B →Jaw
  o L or R or B →Neck
  o L or R or B →Shoulder
  o L or R or B →Elbow
  o L or R or B →Wrist
  o L or R or B →Fingers
  o L or R or B →Hip
  o L or R or B →Tailbone/Back
  o L or R or B →Knee
  o L or R or B →Ankle
  o L or R or B →Toes
o **Lab Order Set:**
  o CBC (w/ differential) + ANA (with titer) + ESR + CRP + CMP
	• Duration of fever: ___# days
	• Description of fever (include all that apply):
	  o Y or N→ ___Continuous
	  o Y or N→ ___Intermittent
	• Y or N→ ___ Responsive to Non-steroidal drug or acetaminophen
	• Y or N→ ___Rash
	• Y or N→ ___Mucocutaneous symptoms
	• Y or N→ ___Joint Pain
	• If Yes, then fill out **Joint Pain** column
	• **Lab Order Set:**
	  o CBC (w/ differential) + ESR + CRP + CMP + ANA (with titer)
		• Reason for ordering ANA (include all that apply):
		  o Y or N→ ___Musculoskeletal pain
		  o Y or N→ ___Fatigue
		  o Y or N→ ___Rash
		  o Y or N→ ___Fevers
		  o ANA titer: 1: ____
		  o Abnormal labs (describe):
		  _____
		  o Other:_____
		  _____
		• **Lab Order Set:**
		  o CBC (w/ differential) + ANA (with titer) + ESR + CRP + CMP

Fig. 3. Referral tool—decision-support tool for providers when considering referral to Pediatric Rheumatology. It has been included in the EMR to facilitate use.
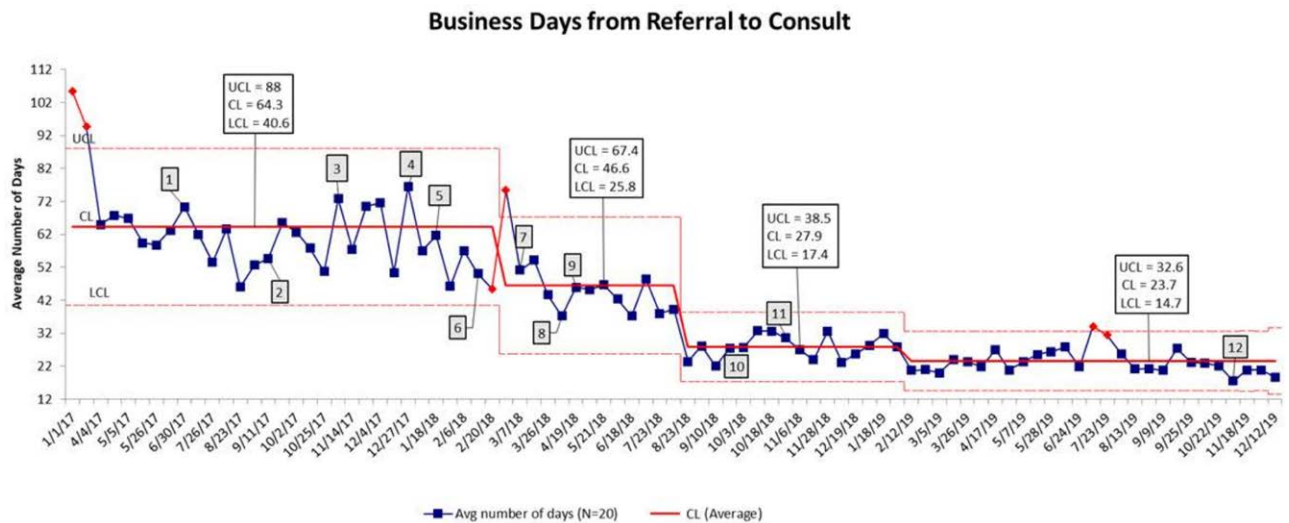
Business Days from Referral to Consult

Fig. 4. Control chart (X chart) demonstrating an average number of business days between referral and initial consult date. Data are divided in samples of 20. Three centerline shifts occurred based on the special cause variation rule of eight successive data points above or below the centerline (mean). 1. The referral tool was introduced to referring providers via both paper and EMR. 2. The referral tool was introduced to providers within our health system at system-wide meeting. 3. Iterations of triage tool revised and implemented. 4. Direct booking appointments closed. 5. Created an education video for providers on referral tool use. Specialty center answering services educated on process to schedule patients based on triage. 6. Two slots held/created on providers schedule to accommodate urgent triage referrals. 7. Triage tool revision and completed education video sent via email to providers. 8. Outside office coordinator teaches back on referral tool use. 9. The second referral tool and survey of providers for facilitators and barriers to use of referral. 10. Hypermobility symptoms and unique triage category added to triage tool. 11. The third presentation of referral tool and survey of providers for facilitators and barriers. 12. The research tool was formally introduced to all provider meetings at one outside hospital. CL, center line; LCL, lower control limit; UCL, upper control limit.

appointments. Buy-in and support from leadership and staff allowed the improvement team to complete numerous PDSA cycles. Success hinged on their appreciation of the value of this extra work in improving access.

The project has significant potential for spread, with applicability beyond pediatric rheumatology practices in other regions. At LCSC, plans are underway to adapt this work in both the Pulmonology and Nephrology clinics.

For example, LCSC's Pulmonology division will shift the triage elements to focus on diseases rather than symptoms.

This project has also spurred additional improvements. During this project, a unique population came to light: 20% of continuous care patients had hypermobile joints causing pain. Further investigation revealed this population might benefit from a multidisciplinary, holistic team approach. Consequently, Rheumatology now offers

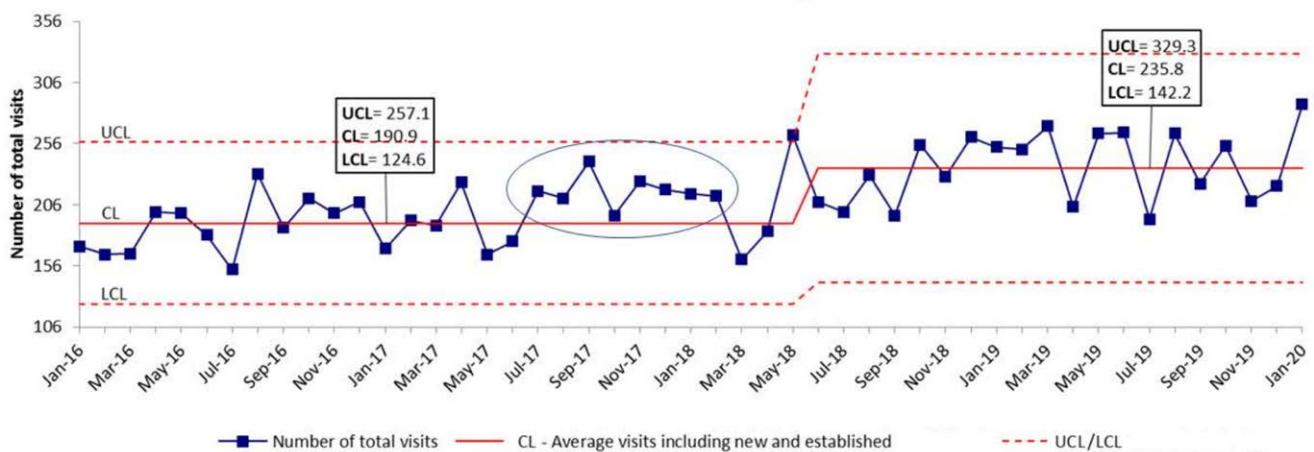**Total Visits to Rheumatology Clinic**

Fig. 5. Control chart (I chart) depicts the total number of new and established visits seen in the Rheumatology Clinic. Numbers evaluated monthly. The upward shift in centerline was based on special cause variation rule of eight successive data points above or below the centerline (mean). Asterisk indicates first sign of special cause, which was not sustained. CL, center line; LCL, lower control limit; UCL, upper control limit.

special twice monthly collaborative sessions for this group to receive rheumatologic medical care, physical therapy, and Reiki in a single visit. Reiki is a natural healing treatment intended to channel energy through gentle touch to encourage deep relaxation of the body and mind to restore physical and emotional well-being. The Reiki specialist also offers guided imagery as a supplement. Furthermore, the sickest of these hypermobile patients now receive care from an ADAPT (arthralgia dysautonomia abdominal pain team) clinic featuring collaboration across Rheumatology, Gastroenterology, Cardiology, Psychology, and General Pediatrics. Last, the original access work is now addressing social disparities by increasing pediatric rheumatology referrals for safety-net clinics in one of Charlotte's lowest socioeconomic zip codes.

Limitations

The addition of a third provider was a factor in the project that may be unique to the LCSC site. This change did allow the clinic to normalize volumes for the original two providers. Although the project goals were achieved without the additional provider, her arrival allowed the project team to exceed the goal and ultimately achieve a 23-day turnaround.

The fact that triage tool reliability only reached 65% means the clinic may have seen more patients than necessary (ie, some of those seen did not have a true rheumatic condition). Nonetheless, the clinic saw everyone who was referred. Clinics with more limited physician availability using this process might be best served by identifying symptoms that fit with priority populations 1 and 2 from the triage algorithm (Fig. 2A).

CONCLUSION

The project succeeded in its initial intent to improve access for pediatric patients in our region needing rheumatologic services. This article showed measurable benefits ranging from significant decreases in wait times and no-show rates to increased capacity and we believe is easily extrapolatable to other hospital systems.

DISCLOSURE

ACKNOWLEDGMENTS

REFERENCES

1. Greenwood-Lee J, Jewett L, Woodhouse L, et al. A categorisation of problems and solutions to improve patient referrals from primary to specialty care. *BMC Health Serv Res*. 2018;18:986.
2. Tzaribachev N, Benseler SM, Tyrrell PN, et al. Predictors of delayed referral to a pediatric rheumatology center. *Arthritis Rheum*. 2009;61:1367–1372.
3. Foster H, Rapley T, May C. Juvenile idiopathic arthritis: improved outcome requires improved access to care. *Rheumatology (Oxford)*. 2010;49:401–403.
4. Correll CK, Spector LG, Zhang L, et al. Barriers and alternatives to pediatric rheumatology referrals: survey of general pediatricians in the United States. *Pediatr Rheumatol Online J*. 2015;13:32.
5. Manners PJ, Bower C. Worldwide prevalence of juvenile arthritis why does it vary so much? *J Rheumatol*. 2002;29:1520–1530.
6. Arthritis Foundation website. Addressing the pediatric rheumatology shortage. Available at https://www.arthritis.org/advocate/federal/addressing-the-pediatric-rheumatology-shortage. Accessed October 7, 2020.
7. Foster HE, Eltringham MS, Kay LJ, et al. Delay in access to appropriate care for children presenting with musculoskeletal symptoms and ultimately diagnosed with juvenile idiopathic arthritis. *Arthritis Rheum*. 2007;57:921–927.
8. Rubinstein TB, Mowrey WB, Ilowite NT, et al; Childhood Arthritis and Rheumatology Research Alliance INVESTIGATORS. Delays to care in pediatric lupus patients: data from the childhood arthritis and rheumatology research alliance legacy registry. *Arthritis Care Res (Hoboken)*. 2018;70:420–427.
9. Provost LP, Murray SK. *The Health Care Data Guide: Learning from Data for Improvement*. 1st ed. Jossey-Bass; 2011.
10. Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap)-A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inf*. 2009;42:377–381.
11. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: building an international community of software partners. *J Biomed Inf*. 2019;95:103208.