Capturing Critical Data Elements in Juvenile Idiopathic Arthritis: Variations between In-person and Virtual Visits and Initiatives to Improve Data Capture

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Abstract

Background: Documentation of critical data elements is a focus of the Pediatric Rheumatology Care and Outcomes Improvement Network to aid in clinical care and research for patients with juvenile idiopathic arthritis. We aimed to increase data capture for arthritis pain score, patient/parent global assessment of wellbeing, provider global assessment, and active joint count. We hypothesized that data capture for all critical data elements would be lower for virtual visits compared to in-person visits.

Methods: All visits for patients with JIA between 9/14/2020 and 12/31/2021 at the University of Minnesota were included. Sixteen interventions with providers were conducted, including email reminders, individual discussions, group meetings, and feedback reports. We used statistical process control charts to evaluate change over time.

Results: Baseline included 355 patient-visits: 221 (62%) in-person and 134 (38%) virtual with critical data elements entry ranging between 50-60%. Post-intervention included 1,596 patient-visits: 1,350 (85%) in-person and 246 (15%) virtual with critical data elements entry of 91%. In-person visits had significantly higher data capture rates than virtual visits for all 4 critical data elements.

Conclusion: We achieved our aim to increase critical data element documentation and found that collection of critical data elements occurred significantly less often with virtual visits than with in-person visits. We inferred that critical data element capture for virtual visits was lower for multiple reasons, including the lack of intake forms and provider uncertainty about scoring certain elements. Now that we improved capture of critical data elements, we can shift the focus to efforts aimed at improving outcomes for patients with juvenile arthritis.

Background:

Juvenile idiopathic arthritis (JIA) is the most common pediatric rheumatic condition with an estimated prevalence of 2 million children worldwide (1). Rapid and sustained disease control is essential to avoid complications such as joint damage, limb growth discrepancies, and vision loss (2). Based on supportive evidence for the use and efficacy of treat-to-target (T2T) in adult patients with rheumatoid arthritis(3) a T2T approach was recommended by an international task force of pediatric rheumatologists for all patients with JIA (4) in order to achieve disease control. A T2T approach sets a target based on shared decision making that is measurable and reassessed over time. An open, single-arm, multicenter study in Germany used T2T for patients with polyarticular JIA and found a statistically significant improvement in disease remission as compared to those who did not use T2T (5).

The Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN), an international quality improvement health network, adopted the T2T approach and, in partnership with an international task force of pediatric rheumatologists (4), developed an aim to increase the percentage of patients with JIA who have inactive to low active disease. Disease activity was defined by the clinical juvenile disease activity score 10 (cJADAS10), a validated tool calculated in real-time using a patient/parent global

assessment of wellbeing (PtGA), active joint count (AJC), and provider global assessment (PrGA). Disease severity cutoffs for oligoarticular and polyarticular JIA have been established, but not for other JIA subtypes (6,7). Steps to achieve PR-COIN's aim of inactive to low active disease include 1) reliable data collection, 2) setting treatment targets with families and patients, and 3) utilizing clinical decision supports to inform treatment. In 2019, PR-COIN tracked the implementation of T2T across PR-COIN sites and reported that only 7 of the 16 sites (43%) were achieving high reliability for data collection, the base step in the process(8). Therefore, efforts to improve data collection were a proposed focus for many sites.

In the spring of 2020, the COVID-19 pandemic created new challenges for the data collection process related to the rapid shift toward virtual visits and a pause in clinical research efforts. PR-COIN lead investigators raised concerns about the reliability and accuracy of the physical exam and assessment of disease activity in a virtual platform (9). Goh, et. al. proposed that additional research should identify ways to improve data collection in virtual visits (9).

The COVID-19 pandemic also provided an opportunity for PR-COIN to revitalize the T2T approach. A PR-COIN consensus conference held in the fall of 2020 recommended incorporation of patient goals when setting targets (10). The original T2T goal was to improve disease activity. Other goals, such as improving patient arthritis pain, were also desired targets (10). Our group wanted to better understand arthritis pain as a target, so we began weekly data collection to determine the current state of arthritis pain relative to disease activity. Manual chart review discovered a critical gap in data collection, with a baseline data collection rate of 52–61% for elements needed to calculate a cJADAS10 and the arthritis pain score. This raised questions about the reliability and accuracy of our data. We therefore aimed to increase data capture for critical data elements (CDEs) which included patient-reported outcomes (PROs), arthritis pain and PtGA, and provider-assessed measures, PrGA and AJC. We also wanted to characterize differences between virtual and in-person visit documentation. We hypothesized that data capture for all CDEs would be lower for virtual visits compared to in-person visits because of altered visit flow and lack of reliable tools that prompt data collection, such as an intake form.

Methods:

Primary and Secondary Outcomes

The primary outcome measure was the proportion of data elements captured into the SmartForm each week out of the total number of JIA patients seen. We initially aimed to have ≥ 80% data collection for arthritis pain and PrGA, and later adjusted our aim as shown in the Results. Secondary outcome measures included the difference between in-person and virtual visit data entry.

Patient Selection

Patients with any JIA subtype, based on International League of Associations for Rheumatology (ILAR) criteria, seen for an in-person or virtual return visit by pediatric rheumatologists and fellows were included. Telephone only visits were excluded. Other exclusions included new patient visits, patients

without a clear diagnosis of JIA, and patients with arthritis related to other diseases such as systemic lupus erythematosus, mixed connective tissue disease, and scleroderma. Three patients diagnosed with systemic JIA without significant arthritis and who had smoldering macrophage activation syndrome were also excluded.

Data Source and Collection

We screened problem lists for all patients scheduled with pediatric rheumatology between 9/14/2020-12/31/2021 at our institution. For patients who met inclusion criteria, we completed a manual chart review of both visit documentation and the electronic medical record (EMR) JIA SmartForm, a data entry tool that allows for data extraction into clinical notes and the PR-COIN Registry. Data found in the provider note but not in the SmartForm did not count in the numerator as these data could not be extracted by the PR-COIN Registry. However, these data elements documented in provider notes but not in the SmartForm were used for individual provider feedback.

Critical data elements reviewed included arthritis pain (0–10 scale with 1.0 increments), PtGA (0–10 scale with 0.5 increments), AJC, and PrGA (0–10 scale with 0.5 increments). Arthritis pain and PtGA are typically assessed on our clinic intake forms and completed by patients/caregivers seen in-person. All data elements for virtual visits and the remaining data elements for in-person visits were collected by the rheumatology provider. All data entered in the SmartForm were dependent on provider entry.

We had between 6–10 providers collecting data during the 68 weeks. Variation in the number of providers related to personal leave, retirement, and new hires.

Interventions

Sixteen provider interventions were tested beginning at week 13, including group email reminders to collect data, individual discussions to personalize workflow adjustments, group meetings to collaborate improvement strategies, and feedback reports (Figs. 1 and 2).

Analysis

Minitab 20.3 (11) software was used. Statistical process control charts evaluated change over time. Shifts were defined as ≥ 8 data points above or below the centerline. New centerlines were calculated based on 12 data points, if available. Inferential statistics included confidence intervals, ANOVA testing, and two-sample t-test.

Results:

Visit characterization

We reviewed a total of 1,953 patient-visits. Table 1 provides baseline and post-intervention totals and weekly statistics.

Table 1
Characteristics of JIA visit types

	Total visits	Weekly Visits		
		Mean	Standard deviation	Range
Baseline: Week 1–12				
Total	355	29.6	6.6	21–46
In-person	221 (62.2%)	18.4	8.8	7–41
Virtual	134 (37.8%)	11.2	5.9	4–25
Post-intervention: Week 13–68				
Total	1598	28.5	7.6	12–46
In-person	1352 (84.6%)	24.1	7.5	9–44
Virtual	246 (15.4%)	4.4	5.1	0–20

Interventions

Figures 1 and 2 illustrate the timeline for the 16 interventions. The initial intervention was an email that established our aim to document arthritis pain and PrGA in ≥ 80% of visits. Baseline data collection rates and a formalized discussion about this aim were reviewed during a group virtual meeting (M1). At our second meeting (M2), we presented the evidence-base for T2T to provide relevance for CDE collection and discussed provider preferences for receiving feedback. Individual meetings with providers occurred subsequently to review each provider's data collection rate and to discuss provider-specific processes, barriers, and suggestions for data collection. Three providers were using an old SmartForm for data entry prior to their individual meetings, but all ultimately adopted the new SmartForm. The most frequently reported challenges with CDE collection were the time required and individual provider concerns about the organization and navigability of the SmartForm.

In a third virtual group meeting (M3), we discussed themes from individual provider meetings, reviewed our improvements in data collection, revised our aims, and elicited group input on preferences for feedback reports. We established new aims to document arthritis pain and PtGA for ≥ 90% of visits and PrG and AJC for ≥ 80% of visits. New feedback reports included group and provider-specific data on the percent of patient-visits each week with arthritis pain ≤ 3 and a breakdown of disease activity.

Control P-charts

Control charts were initially separated into virtual and in-person visits for each CDE to analyze how interventions impacted documentation based on visit type. However, the proportion of virtual visits decreased substantially in the post-intervention period, which made virtual visit control charts limits

widely variable. This was confirmed via ANOVA testing which revealed significant differences (p-value < 0.001) in the proportion of virtual visits at baseline (mean 0.39, 95% CI 0.27–0.51) and post-intervention weeks 13–32 (mean 0.31, 95% CI 0.24–0.38) as compared to post-intervention weeks 33–68 (mean 0.06, 95% CI 0.04–0.07). Therefore, final control chart analysis incorporated the combination of virtual and in-person visits.

Baseline data entry of CDEs for all visit types ranged between 52–61%. Email reminders and group meetings (M1 and M2) improved arthritis pain and PtGA data entry to ≥ 80%, as shown by the upward shift at week 21 (Fig. 1A-B). AJC and PrGA documentation shifted upward later at week 45 (Fig. 2A-B) which occurred after intervention M3. Additional shifts occurred when providers received monthly feedback reports with patient pain and disease activity scores (Figs. 1 and 2).

In-person versus virtual care

We separated the comparison of in-person and virtual visit documentation into three phases based on visit type proportions. Regardless of phase, in-person visits had significantly higher data capture rates than virtual visits for all four CDEs (Table 2).

Table 2
Two-Sample T-Tests for CDE Collection Ratios Between In-person and Virtual Visits

	Phase 1 (week 1–12)		Phase 2 (week 13–32)		Phase 3 (week 33–68)	
	Mean (Standard deviation)	p-value	Mean (Standard deviation)	p-value	Mean (Standard deviation)	p-value
Arthritis Pain						
Office	0.73 (0.13)	< 0.001*	0.86 (0.11)	0.001*	0.88 (0.07)	< 0.001*
Virtual	0.38 (0.19)		0.60 (0.27)		0.39 (0.42)	
Patient Global Assessment						
Office	0.73 (0.12)	< 0.001*	0.85 (0.11)	< 0.001*	0.87 (0.08)	< 0.001*
Virtual	0.39 (0.18)		0.56 (0.28)		0.36 (0.41)	
Active Joint Count						
Office	0.69 (0.16)	< 0.001*	0.70 (0.12)	< 0.001*	0.81 (0.16)	< 0.001*
Virtual	0.26 (0.16)		0.27 (0.24)		0.34 (0.39)	
Provider Global Assessment						
Office	0.65 (0.15)	< 0.001*	0.72 (0.14)	< 0.001*	0.81 (0.14)	< 0.001*
Virtual	0.26 (0.19)		0.32 (0.23)		0.39 (0.40)	

Discussion:

Reliable data collection is necessary to accurately assess outcomes but has been a major challenge at many PR-COIN sites, with our site being one of those. Aided by quality improvement processes, we achieved our aim of increasing CDE documentation for arthritis pain, PtGA, PrGA, and AJC by first characterizing our data collection and then focusing on provider buy-in, frequent reminders, and individualized feedback. Data characterization also demonstrate that the capture of CDEs occurred significantly less often with virtual than with in-person visits; however, when assessing our improvements, we grouped visit types together due to a sharp decline over time in virtual visits, limiting assessment of improvements for these separately.

Improved documentation of PROs occurred several weeks prior to improvement in provider-assessed measures, despite initially targeting arthritis pain and PrGA. We postulate that multiple factors contributed to these differences, including the use of an intake form for PROs, appearance and position of CDEs on the SmartForm, time commitment, and provider level of comfort associated with each CDE. Similar to the majority (84%) of PR-COIN sites, we use paper intake forms to collect PROs during in-person visits (9). Parallel improvements were observed for arthritis pain and PtGA, which we hypothesize was due to the use of an intake form and the location of these PROs at the top of the SmartForm. The difference in time required to obtain two PROs rather than just one is minimal, which likely explains why PtGA improved in parallel with arthritis pain despite our not targeting PtGA initially.

Improvement in collection of PrGA did not occur until week 45, despite targeting it at week 13. Providers disclosed having no formal education on how to rate a PrGA and discomfort with assessing PrGA virtually. The lack of concordance of interrater scoring for PrGA has been demonstrated previously(12) and highlights the need for systematic training and well-defined guides for rating PrGA. We postulate this intervention would result not only in more reliable data collection but also a more accurate assessment of the patient's clinical status. Additionally, PrGA is located at the bottom of the SmartForm which requires scrolling and may have contributed to lower data capture initially.

Documentation of AJC promptly occurred after we set an aim to improve its collection. This was observed as virtual visit frequency declined. Limitations discussed for AJC capture included redundancy and extra time commitment counting the AJC number since provider notes had more descriptive joint findings.

Provider interest in personalized feedback regarding patient outcomes, specifically patient disease activity scores, as opposed to the provider's ability to capture data seemed to motivate documentation. The cJADAS10 requires collection of PtGA, PrGA, and AJC for each patient. The proposal to collect and report feedback on patient disease activity during M3, resulted centerline shifts > 90% for all CDE.

Limitations

Generalizability is a limitation since institutions have different processes, resources, EMRs, and virtual visit frequencies. For example, our utilization of the SmartForm was the major tool for tracking the CDEs. Not all sites have the same EMR system or SmartForm. Additionally, resource differences, such as paper

intake versus electronic intake forms, would likely contribute to differences in data collection. Even though these processes may differ, the concepts of tracking data and providing individual feedback can be generalized.

Another limitation included the decline in virtual visit numbers over time which may have skewed the data when comparing virtual to in-person data collection. We attempted to compensate for this by splitting data into phases.

Future directions

Reliance on manual chart review was key to this project's success. In the longer term, a more automated process is needed. Ideally, we would have electronic questionnaires that input PROs directly into the SmartForm. Such a platform for data entry would likely improve data capture for both in-person and virtual visit PRO collection. The SmartForm is intended to facilitate extractable data, which is pushed into the PR-COIN Registry, a centralized database whose output is similar to the feedback reports we have been manually generating. Feedback reports created by PR-COIN and presented to individual sites could facilitate improved data entry for all metrics, including provider-assessed measures. Systematic training for PrGA and validating virtual visit assessment of AJC is also a necessary next step to improve both documentation and validity data.

Conclusion:

In conclusion, our work highlights the necessary building blocks for improved outcomes in patients with JIA. Reliable CDE collection is an essential step to utilizing validated disease activity scores to inform T2T strategies and ultimately improving patient outcomes.

Abbreviations:

AJC
Active Joint Count
CDE
Critical Data Elements
JIA
Juvenile Idiopathic Arthritis
PR-COIN
Pediatric Rheumatology Care and Outcomes Improvement Network
PrGA
Provider Global Assessment
PROs
Patient Reported Outcomes
PtGA

Patient Global Assessment of Overall Wellbeing
T2T
Treat-to-target

Declarations

Ethics approval: The University of Minnesota Institutional Review Board waived formal approval since this was a quality improvement project.

Consent for publication: Not applicable.

Availability of data and materials: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interest: No authors have relevant financial disclosures or competing interests.

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Author contributions: MER designed, acquired, analyzed, and interpreted the data and drafted and made major revisions to this manuscript. DB mentored MER regarding the design, acquisition, analysis, and interpretation of the data and made substantial revisions to the draft. AW mentored MER in the analysis and interpretation of statistical processes and quality improvement methodology. BB, CC, EH, PH, AL, SM, MMR, ZS, and RV contributed to data entry and made substantial revisions to the draft.

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Figures

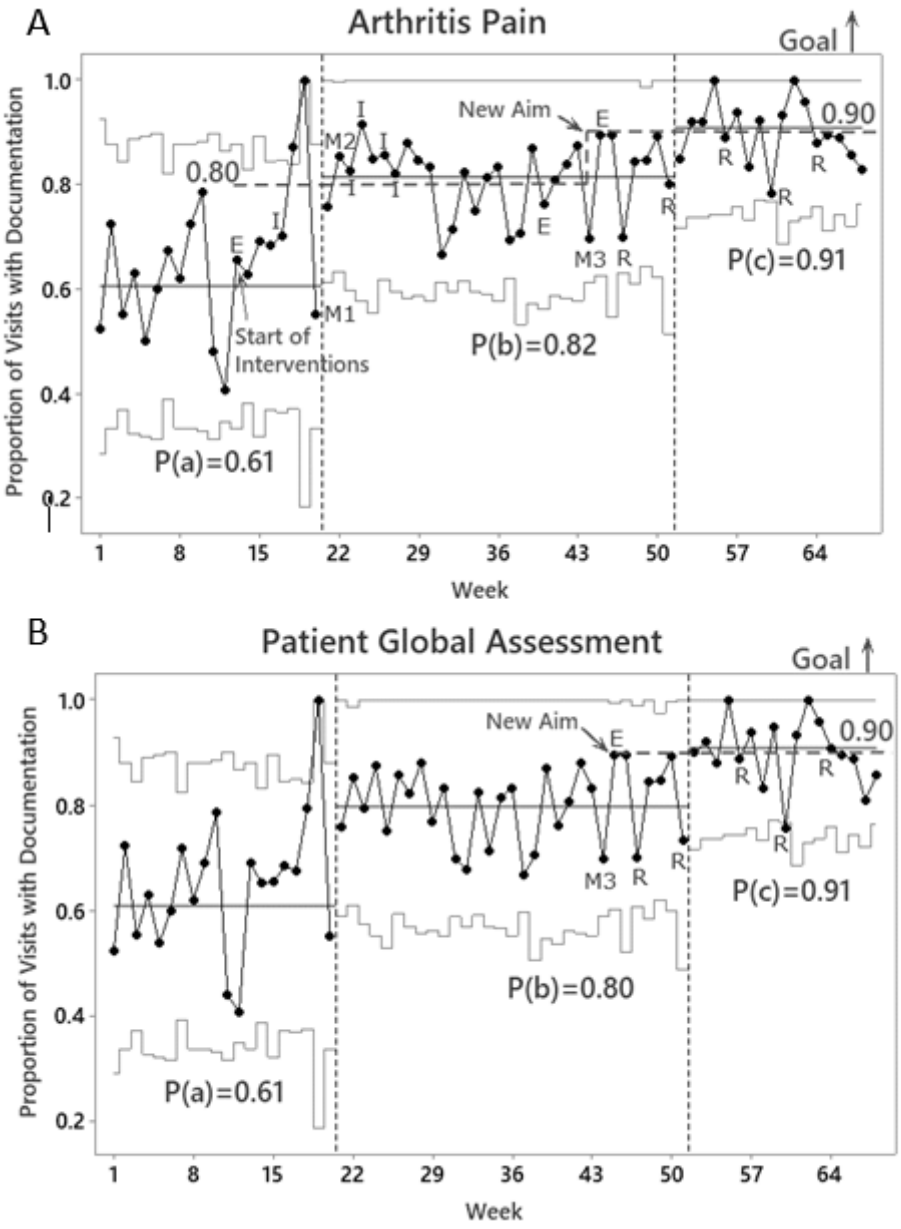

Figure 1

Control P-Charts of Documentation for Patient-Reported Outcomes. Data points are charted over time. Solid black lines represent means calculated based on 12 consecutive points for each interval, P(a) = weeks 1-12, P(b) = weeks 21-32 and P(c) weeks 52-63. Dotted lines represent aims. Solid grey lines represent control limits. Upward shifts occurred at weeks 21 and 52 for both A and B.

E = email; I = individual discussions; M= group meetings; R = feedback reports.

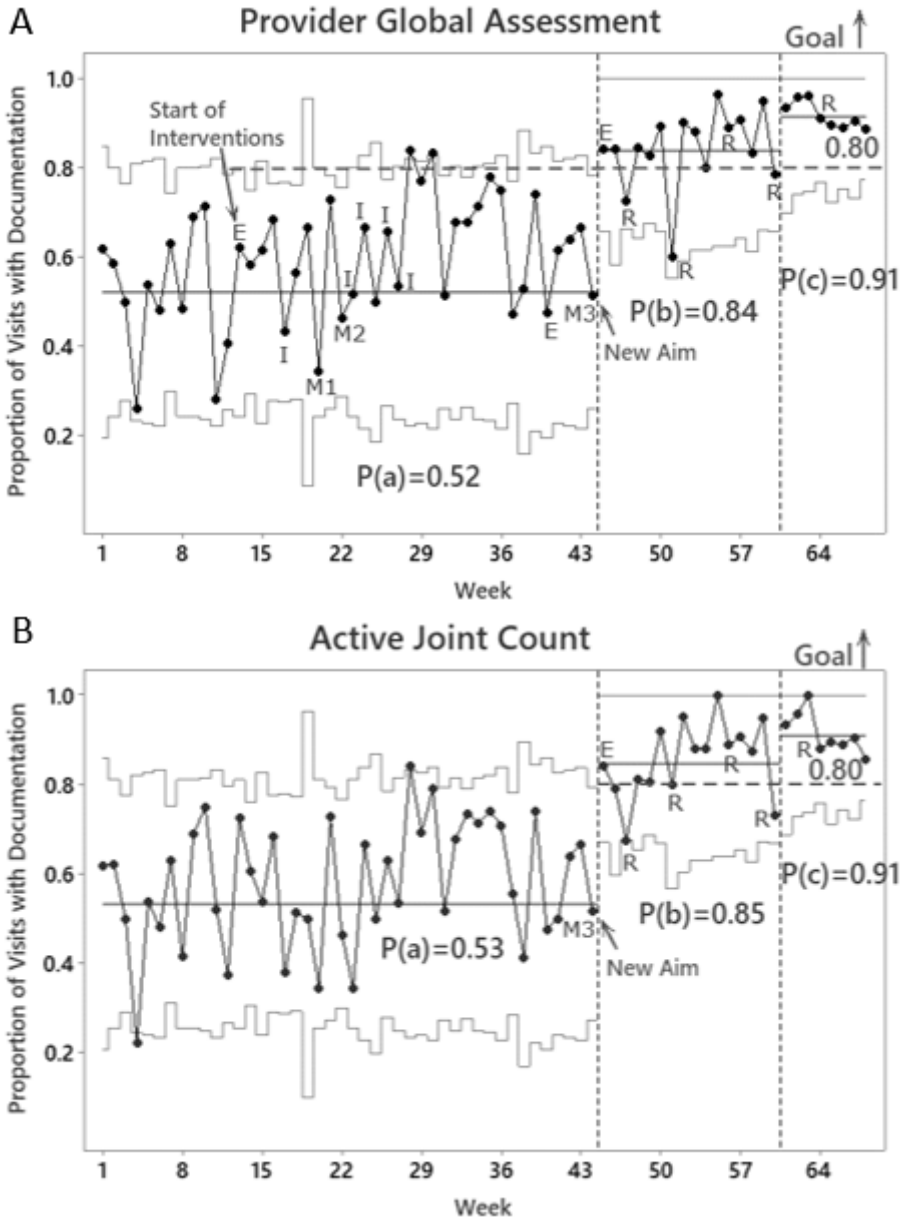

Figure 2

Control P-Charts of Documentation for Provider-Assessed Measures. Data points are charted over time. Solid black lines represent means calculated based on 12 consecutive points for each interval, P(a) = weeks 1-12, P(b) = weeks 45-56 and P(c) weeks 61-68. Dotted lines represent aims. Solid grey lines represent control limits. Upward shifts occurred at weeks 45 and 61 for both A and B.

E = email; I = individual discussions; M= group meetings; R = feedback reports.