The Journal of Rheumatology 2022;49:497–503
doi:10.3899/jrheum.210709
First Release March 15 2022

The Journal of Rheumatology

Consensus Approach to a Treat-to-target Strategy in Juvenile Idiopathic Arthritis Care: Report From the 2020 PR-COIN Consensus Conference

Tala El Tal[1], Meghan E. Ryan[2], Brian M. Feldman[1], Catherine April Bingham[3], Jon M. Burnham[4], Michelle Batthish[5], Danielle Bullock[2], Kerry Ferraro, Mileka Gilbert[6], Miriah Gillispie-Taylor[7], Beth Gottlieb[8], Julia G. Harris[9], Melissa Hazen[10], Ronald M. Laxer[1], Tzielan Chang Lee[11], Daniel Lovell[12], Melissa Mannion[13], Laura Noonan[14], Edward Oberle[15], Janalee Taylor[12], Jennifer E. Weiss[16], Cagri Yildirim Toruner[7], and Esi M. Morgan[17]

ABSTRACT. ***Objective.*** Treat to target (T2T) is a strategy of adjusting treatment until a target is reached. An international task force recommended T2T for juvenile idiopathic arthritis (JIA) treatment. Implementing T2T in a standard and reliable way in clinical practice requires agreement on critical elements of (1) target setting, (2) T2T strategy, (3) identifying barriers to implementation, and (4) patient eligibility. A consensus conference was held among Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) stakeholders to inform a statement of understanding regarding the PR-COIN approach to T2T.

Methods. PR-COIN stakeholders including 16 healthcare providers and 4 parents were invited to form a voting panel. Using the nominal group technique, 2 rounds of voting were held to address the above 4 areas to select the top 10 responses by rank order.

Results. Incorporation of patient goals ranked most important when setting a treatment target. Shared decision making (SDM), tracking measurable outcomes, and adjusting treatment to achieve goals were voted as the top elements of a T2T strategy. Workflow considerations, and provider buy-in were identified as key barriers to T2T implementation. Patients with JIA who had poor prognostic factors and were at risk for high disease burden were leading candidates for a T2T approach.

Conclusion. This consensus conference identified the importance of incorporating patient goals as part of target setting and of the influence of patient stakeholder involvement in drafting treatment recommendations. The network approach to T2T will be modified to address the above findings, including solicitation of patient goals, optimizing SDM, and better workflow integration.

Key Indexing Terms: disease activity score, juvenile idiopathic arthritis, outcomes, physician practice patterns, practice guidelines, registries

Juvenile idiopathic arthritis (JIA) refers to several types of chronic arthritis of unknown etiology affecting children before the age of 16 years. The International League of Associations for Rheumatology proposed a uniform definition and classification criteria for JIA.[1] In practice, available numbers of incidence and prevalence of JIA vary widely, in part due to the heterogeneity of JIA and differing means of case ascertainment.[2] The estimated incidence rate of

This study was supported by Patient-Centered Outcomes Research Institute (PCORI) grant RI-PCC-2017.

[1]T. El Tal, MD, B.M. Feldman, MD, PhD, R.M. Laxer, MD, The Hospital for Sick Children, and University of Toronto, Toronto, Ontario, Canada; [2]M.E. Ryan, DO, D. Bullock, MD, University of Minnesota, Minneapolis, Minnesota, USA; [3]C.A. Bingham, MD, Penn State Children's Hospital, Hershey, Pennsylvania, USA; [4]J.M. Burnham, MD, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA; [5]M. Batthish, MD, McMaster University, Hamilton, Ontario, Canada; [6]M. Gilbert, MD, Medical University of South Carolina, Charleston, South Carolina, USA; [7]M. Gillispie-Taylor, MD, C. Yildirim Toruner, MD, Texas Children's Hospital Baylor College of Medicine, Houston, Texas, USA; [8]B. Gottlieb, MD, Cohen Children's Medical Center, Lake Success, New York, USA; [9]J.G. Harris, MD, Children's Mercy Kansas City, Kansas City, Kansas, USA; [10]M. Hazen, MD, Boston Children's Hospital, Boston, Massachusetts, USA; [11]T.C. Lee, MD, Stanford Children's Health, Palo Alto, California, USA; [12]D. Lovell, MD, J. Taylor, CNP, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA; [13]M. Mannion, MD, University of Alabama at Birmingham, Birmingham, Alabama, USA; [14]L. Noonan, MD, Levine Children's Hospital/Carolinas Healthcare System, Charlotte, North Carolina, USA; [15]E. Oberle, MD, Nationwide Children's Hospital, Columbus, Ohio, USA; [16]J.E. Weiss, MD, Hackensack University Medical Center, Hackensack, Hackensack, New Jersey, USA; [17]E.M. Morgan, MD, MSCE, University of Washington, and Seattle Children's Hospital, Seattle, Washington, USA.

T. El Tal and M.E. Ryan are co-first authors.

The authors declare no commercial financial conflict of interest relevant to this article.

Address correspondence to Dr. E.M. Morgan, Seattle Children's Hospital, Division of Rheumatology, 4800 Sand Point Way NE, Seattle, WA 98105, USA. Email: Esi.Morgan@seattlechildrens.org.

Accepted for publication January 21, 2022.

JIA varies globally across different populations, ranging from 1.6 to 23 per 100,000 individuals..[3]

All forms of JIA can be associated with significant disease- and treatment-related morbidity, thus affecting children's health-related quality of life (QOL).[4,5] The probability of attaining remission within 5 years of diagnosis is approximately 50%, except for children with polyarthritis.[6] Only approximately 40% of children with a polyarticular form of JIA achieved disease control.[7] Many children with JIA continue to have arthritis with associated morbidities and QOL impairments into their adulthood.[8] Relative to historical cohorts, there is suggestive evidence that early disease control in JIA can lead to lower rates of permanent joint damage.[9] Thus, it is imperative to focus care delivery on tighter disease control to improve outcomes for patients. This approach is in line with the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) mission and vision.

Established in 2011, PR-COIN is a collaborative learning health network of 21 pediatric rheumatology centers across the US and Canada, who, in partnership with patients and families, work together to ensure the best delivery of care with a focus on outcomes improvement.[10] PR-COIN employs a modified version of the Institute for Healthcare Improvement's Breakthrough Series collaborative model,[11] described here. After selecting an evidence-based topic and designing an intervention, teams come together to learn about the intervention, and then return to their centers for an "action period" to test the intervention iteratively in clinical practice using plan-do-study-act cycles over 18 months. Teams meet monthly by webinar to share performance data, learning, and best practices. Then, teams reconvene in longer learning sessions every 6 months to discuss progress. This growing network utilizes evidence-based interventions such as previsit planning, population management, self-management tools, shared decision making (SDM), and patient/parent engagement, to improve chronic illness care.[12] Several of these interventions overlap with the proposed principles of treat to target (T2T).

T2T refers to a target-based treatment approach in which patients and providers select a treatment target that is frequently monitored using measurable outcomes to adjust therapeutic interventions.[13] SDM with the clinical care team and patient/parent is a central principle of the T2T approach. To date, there is growing evidence that supports the use and efficacy of T2T in chronic rheumatic diseases, particularly in rheumatoid arthritis (RA). Ramiro et al showed that when a T2T strategy is appropriately applied in a clinical setting, it results in better remission outcomes.[14] While many studies followed and reinforced the efficacy of T2T in RA,[15] the evidence of T2T use in improving outcomes in patients with JIA is more limited.

In 2018, an international task force of rheumatologists recommended the incorporation of the T2T paradigm for all patients with JIA.[16] Treatment targets aimed to achieve clinical remission, with an alternative goal of low disease activity (LDA). A list of instruments and criteria used to define clinically inactive disease and LDA was suggested.[16] The task force provided recommendations for frequency of evaluations, expectations for timing of improvement, and ways to incorporate the patients and families into the decision making. Buckley et al published a pilot center experience study showing how implementation of structured disease activity monitoring paired with clinical decision support significantly improved Clinical Juvenile Arthritis Disease Activity Score (cJADAS) scores, a validated clinical disease activity measure, in both early and established polyarticular JIA.[17] Based on the evidence supporting T2T as a treatment approach in rheumatology and the T2T task force recommendations for JIA, PR-COIN leadership decided to test T2T as a strategy to drive outcomes improvement. The PR-COIN Outcomes Committee, comprising network participants selected based on expertise with quality improvement (QI) and history of best practice performance, designed a T2T intervention to be tested at interested PR-COIN centers. Educational modules were developed, with parent stakeholder input, for training teams on T2T components, use of SDM medication issue cards augmented with cJADAS calculations,[18] treatment algorithms, and parent/patient-facing materials (handout, video) describing the T2T approach. The intervention was presented at a learning session in January 2019, and materials were distributed to PR-COIN centers for use during the action period. Testing of the intervention began with the patients with extended oligoarticular and polyarticular JIA.

In February 2019, 16 PR-COIN centers proceeded to test the T2T interventions in their local clinic settings, with an emphasis on using a stepwise adoption of (1) setting a treatment target with the patient/family, (2) standardizing disease activity assessment and comparing the target to the current disease state, and (3) utilizing a treatment escalation algorithm, a form of clinical decision support.[19] Centers aimed to achieve ≥ 80% reliability of performance for each of the 3 steps. Of the 16 PR-COIN centers who tested the T2T intervention, 7 centers reported setting targets with patients and families, 8 reported achieving 80% reliability in assessing disease activity in a standard way, and 3 centers reported using standardized treatment escalation algorithms.[19]

In preparation for the formal implementation of the intervention, with a plan for subsequent scale-up and spread to other pediatric rheumatology centers, we scheduled a consensus conference to gain robust feedback from centers now experienced in testing the components of the intervention, and to understand any barriers encountered with implementation. The purpose was to understand how the intervention might need to be adapted based on the center experience with testing in their local contexts. PR-COIN is a patient-centered organization, and therefore we incorporated parent stakeholders who had experienced the intervention as part of their child's care.

Specific questions asked at the consensus meeting were developed by the meeting facilitator (BMF) and network principal investigator (EMM), with review by the leaders of the T2T intervention (JMB, JGH). The 4 fundamental questions about the T2T intervention, for which the answers would be informed by experiences of testing centers, included the following:

1. What are the most important elements when setting an individual's target, that considers the points of view of both the patient/family and the healthcare team?

2. What are the most important elements of a T2T strategy?
3. What are the most important barriers to implementing a T2T strategy?
4. Who are the most important patients/patient groups to enroll in a T2T strategy?

METHODS

PR-COIN has an umbrella institutional review board protocol governing network activities. Participation in the consensus meeting was by invitation to participating PR-COIN members to improve a QI intervention. Consent was implied by acceptance to attend. Voting members included clinician principal investigators from PR-COIN centers who had participated in the 2019 T2T intervention, or a clinical leader delegate, along with parents who participated in the PR-COIN team at the center their child receives care. Patients were invited but did not attend the meeting as it occurred during school hours. The facilitator (BMF) was an expert in consensus methods and the nominal group technique (NGT). PR-COIN Fellowship Program participants assisted with data collection for voting polls (TET, MER). There was a designated notetaker (JT). The conference was held as a virtual meeting over the Zoom platform.[20] Meeting proceedings were recorded.

Prior to the consensus voting session, the participants listened to brief motivational talks by a PR-COIN Outcomes Committee leader (JMB) and a parent advocate and author of an editorial on T2T from a parent perspective.[21] Educational speakers included coauthors of the T2T task force recommendations and an author of a publication on experience with T2T in a European cohort.[16,22] These educational sessions aimed to share T2T task force recommendations, show real-world evidence of effectiveness, describe clinical experience with implementation (JGH), and highlight the patient perspective that was absent from the original task force recommendations. Reference papers were sent to the voting panel in advance.[16,18,21–26] Invitations were sent to a broader community audience to listen to the preconsensus meeting educational sessions, and then to the presentation of consensus voting results. Invitees included PR-COIN member center teams, parent work group members, Arthritis Foundation representatives, Childhood Arthritis and Rheumatology Research Alliance (CARRA) leaders participating in shared research contracts, JIA researchers, allied healthcare providers and speakers at the PR-COIN learning session (held the following day), and the expert speakers (see Acknowledgment). The general attendees did not attend the consensus voting session. Patients were invited but were unable to attend since the meeting occurred during school hours.

The NGT was used to obtain consensus among voting members on the top 10 items for each question.[27] The 4 research questions, listed above, served as open-ended questions asked by the facilitator, for 2 voting rounds per question; the voters were given 5 minutes to brainstorm before discussion. Then, each voting member presented a single unique answer per round until all answers were stated. Answers were recorded simultaneously by the pollsters into an electronic polling software, Poll Everywhere,[28] and voting members were able to view these answers.

Each participant placed 7 total votes on answers they thought were of the highest significance. Members were allowed to place as many of their 7 votes on a single answer as they desired. Once all votes were recorded, the pollsters revealed the top 10 items for the respective round.

The facilitator initiated a second round of discussion in which each voting member advocated for and clarified their votes for the answers to the original question. A new poll was created to reflect any changes, and a second round of voting occurred. The final top 10 items for the question were revealed in rank order, reflecting a pooled outcome of the individual votes.

RESULTS

On October 22, 2020, a PR-COIN Consensus Conference was held virtually using the Zoom platform. Twenty total voting members were recruited including 16 healthcare providers, 1 parent/clinician, and 3 parents (see Supplementary Table 1, available with the online version of this article).

Questions 1–3 resulted in > 50 answers per round and question 4 resulted in > 20 answers (Supplementary Table 2, available with the online version of this article). Tables 1–4 show the top 10 items from each round based on total votes. Next to each question response in the tables, we included the total number of votes and the percentage of participants who voted on the item. Notably, some responses ranked higher on the list based on the total number of votes received but had relatively lower percentages of total voters endorsing the item. This finding was related to individual voters placing multiple votes on an individual response (as described in Methods).

Question 1 elicited the most important elements of target setting in T2T. Results from 2 rounds of voting are presented in Table 1. Between the 2 voting rounds, there was relative

Table 1. Top-ranked answers from 2 voting rounds for question 1: setting the target.

Question 1: What are the most important elements when setting an individual's target, that considers the points of view of both the patient/family and the healthcare team?	
Round 1: 140 responses, 20 voters	Round 2: 140 responses, 20 voters
1. Patient goals (17 votes, 70%)	1. Patient goals (21 votes, 100%)
2. Disease activity score (cJADAS) (15 votes, 60%)	2. Disease activity score (cJADAS) (18 votes, 80%)
3. Quality of life (13 votes, 65%)	3. Pain domain (16 votes, 70%)
4. Functional ability (9 votes, 45%)	4. Quality of life (12 votes, 60%)
5. Joint count (9 votes, 40%)	5. Medication domain (12 votes, 60%)
6. Family/patient preference for medications (8 votes, 35%)	6. Presence of risk factors for poor outcomes (8 votes, 40%)
7. Joint damage or complications of disease (7 votes, 35%)	7. Joint count (7 votes, 25%)
8. Amount of pain (7 votes, 35%)	8. Functional ability (6 votes, 30%)
9. Social participation (6 votes, 30%)	9. Pain interference (6 votes, 25%)
10. Pain interference (5 votes, 25%)	10. Social participation (5 votes, 25%)

cJADAS: Clinical Juvenile Arthritis Disease Activity Score.

Table 2. Top-ranked answers from 2 voting rounds for question 2: elements of treat to target (T2T).

Question 2: What are the most important elements of a T2T strategy?	
Round 1: 119 responses, 17 voters	Round 2: 126 responses, 18 voters
1. Shared decision making (16 votes, 88%)	1. Shared decision making (19 votes, 100%)
2. Training of providers and patients on the T2T strategy (10 votes, 59%)	2. Clearly measurable outcomes (17 votes, 89%)
3. Frequent assessment of activity and target status (9 votes, 53%)	3. Adjustment of treatment to meet goals (12 votes, 83%)
4. Clearly measurable outcomes (8 votes, 41%)	4. Incorporation of T2T into clinic workflow (12 votes, 67%)
5. Patient's individual target (7 votes, 35%)	5. Training of providers and patients on the T2T process (10 votes, 56%)
6. Adjustment of treatment to meet goals (6 votes, 35%)	6. Patient's individual target (9 votes, 50%)
7. Defining a target for JIA subtype (6 votes, 35%)	7. Frequent assessment of activity and target status (9 votes, 39%)
8. Use of clinical decision support (5 votes, 29%)	8. Provider, patient, and family buy-in (7 votes, 39%)
9. Provider, patient, and family buy-in (5 votes, 29%)	9. Data collection into registry/EMR (with display feature) for patients to review their own progress (6 votes, 28%)
10. Standardized measurement of the outcome (4 votes, 24%)	10. Use of clinical decision support (5 votes, 28%)
11. Incorporation of T2T into clinic workflow (4 votes, 24%)	

EMR: electronic medical record; JIA: juvenile idiopathic arthritis.

Table 3. Top-ranked answers from 2 voting rounds for question 3: barriers to implementation.

Question 3: What are the most important barriers to implementing a treat-to-target (T2T) strategy?	
Round 1: 20 voters, 140 responses	Round 2: 20 voters, 140 responses
1. Lack of incorporation of T2T into workflow (19 votes, 90%)	1. Lack of incorporation of T2T into workflow (21 votes, 90%)
2. Clinician time constraints (17 votes, 75%)	2. Lack of buy-in domain (17 votes, 85%)
3. Lack of technology for clinical decision support at individual patient level (7 votes, 30%)	3. Lack of resource domain (15 votes, 75%)
4. Lack of buy-in on concepts of shared decision making (6 votes, 30%)	4. Clinician time constraints (14 votes, 55%)
5. Clinician's reluctance to respond to a fixed target (6 votes, 30%)	5. Virtual care: inability to capture information needed (10 votes, 50%)
6. Practice variability among medical providers within centers and network (6 votes, 30%)	6. Patient nonadherence (9 votes, 45%)
7. Virtual care: inability to capture information needed (6 votes, 30%)	7. Change management in providers and staff (9 votes, 45%)
8. Lack of standardized documentation (5 votes, 25%)	8. Resistance to change by providers and families (6 votes, 30%)
9. Lack of commitment to T2T across all members/leadership of pediatric rheumatology division (5 votes, 25%)	9. Different perceptions and expectations of patients and clinicians (5 votes, 25%)
10. Lack of access to treatment options (5 votes, 25%)	10. Technical barriers: inability to record PROM responses directly into EMR (4 votes, 20%)
11. Lack of buy-in due to lack of evidence to date (5 votes, 25%)	

EMR: electronic medical record; PROM: patient-reported outcome measure.

stability in the top 10 ranked elements, with 7 of the initial elements continuing into the second round. Patient goals ranked first in both rounds of voting, and disease activity, as captured by the cJADAS, ranked second. Between rounds 1 and 2, participants advocated for the importance of patient goals and disease activity, and discussed consolidation of similar themed

Table 4. Top-ranked answers from 2 voting rounds for question 4: who to enroll?

Question 4: Who are the most important patients/patient groups to enroll in a treat-to-target (T2T) strategy?	
Round 1: 20 voters, 140 responses	Round 2: 19 voters, 133 responses
1. All patients with JIA (25 votes, 60%)	1. All patients with JIA (27 votes, 58%)
2. All patients (13 votes, 30%)	2. Patients with poor prognostic factors (15 votes, 68%)
3. Patients with any condition in which disease activity is linked with damage (11 votes, 45%)	3. Patient with a high disease burden (13 votes, 63%)
4. Patients with diagnoses where targets are defined[a] (11 votes, 40%)	4. Newly diagnosed patients with JIA (12 votes, 63%)
5. Patients with diagnoses for which a T2T approach is supported by evidence-based medicine (literature) (9 votes, 40%)	5. Patients from diverse racial and ethnic backgrounds should be included (10 votes, 42%)
6. Patients with JIA with active disease (9 votes, 40%)	6. Patient with any condition in which disease activity is linked with damage (9 votes, 32%)
7. Patients with high disease burden (9 votes, 40%)	7. Patients with JIA with active disease (8 votes, 42%)
8. Patients seen by multiple providers (9 votes, 35%)	8. Patients with JIA with a flare (7 votes, 37%)
9. Newly diagnosed patients with JIA (8 votes, 40%)	9. Patients with diagnoses where targets are defined[a] (6 votes, 37%)
10. Patients with JIA with a flare (7 votes, 35%)	10. Patients seen by multiple providers (6 votes, 26%)

[a] There are standard measures of disease activity with cut points for inactive disease vs low disease activity. JIA: juvenile idiopathic arthritis.

answers into domains, such as the pain and medication domains. Pain, QOL, and medication domains were also thought to be important by more voters.

Question 2 aimed to identify the most important elements that should be included in a T2T strategy. The top 10 ranked elements between each of the rounds were similar, with differing prioritizations (Table 2). SDM was consistently the most important element in each round. Participants discussed the practical pieces necessary for a T2T strategy, which included the use of clearly measurable outcomes and the adjustment of treatments to meet goals throughout a patient's course. Participants also discussed how a successful T2T process requires buy-in from the patient, family, and clinician. Training patients and clinicians and optimizing the use of the electronic medical record as a tool were also discussed as key for implementing a T2T strategy.

Question 3 focused on identifying the top 10 barriers to the implementation of T2T (Table 3). During the first round, most votes were given to the lack of incorporation of T2T into clinic workflow and to clinician time constraints; these were also endorsed as important in the second round. A discussion between rounds focused on understanding the variability that exists among sites and individual clinicians. This discussion prompted consolidating concepts of the lack of buy-in of elements of the T2T process at the provider, patient, or leadership at the pediatric rheumatology division level into a single domain. Similarly, lack of resources available for T2T was consolidated into 1 domain.

Question 4 asked the voters to decide on which patients would be most suitable to enroll into a T2T strategy (Table 4). Discussion between rounds shifted from a "good for all" type of approach (ie, to apply a T2T strategy to all diagnoses and all patients) to the prioritization of patients with JIA to mitigate risks of ongoing active disease, particularly those at risk for high disease burden, poor outcomes (prognostic factors), and health disparities. Newly diagnosed patients were also important to include in a T2T strategy due to potential for a treatment window of opportunity.

DISCUSSION

PR-COIN conducted a consensus meeting to understand community priorities and reach agreement on key elements of a T2T strategy based on participants' experience with testing T2T in their local centers. The findings are intended to inform adaptations of the T2T intervention prior to additional testing, implementation, scale-up, and spread. A central theme was the recognition of patients as key stakeholders in the intervention. This was evidenced by the unanimous vote for the incorporation of patient goals as the most important consideration when setting a patient's target in question 1, with an emphasis on specifically asking patients/parents about individual goals rather than assuming their goal of LDA or inactive disease. The inclusion and high endorsement of patient-centered goals may reflect the presence of parents on the voting panel, and the moving presentation delivered by a parent prior to the voting session that emphasized the importance of the patient's voice in their treatment. In order to actualize this perspective as a network, consideration is needed to execute the following: (1) better define a scope of goals; (2) learn how to do goal setting with patients; (3) identify how to capture and document patient goals and track them over time; and (4) devise how to measure progress (individually for patients and network-wide) longitudinally and tailor treatment accordingly. The disease activity score,

which is included in the current T2T strategy, continued to be an important target as well. Understandably, having a standard target with validated measurement properties (ie, cJADAS) enables comparison of progress within a single patient over time, across patients, and across centers. It is imperative to not only continue standard assessment of disease activity but also add patient goals in the target setting.

Another central theme of this consensus meeting was SDM, which continued to be regarded as a key overarching principle of the T2T approach for patients with JIA. A previous review demonstrated that the majority of parents are interested in SDM.[29] El Miedany et al recently showed how an interactive SDM aid offered children with JIA evidence-based information about the pros and cons of treatment options and improved their understanding of the disease and their ability to make an informed decision. In turn, this significantly improved patient adherence to therapy, patient-reported outcomes, and number of absences from school compared to the control group.[30] As such, with respect to elements of a T2T strategy, SDM is an area that may deserve renewed focus.

Voters also discussed the importance of considering health disparities as part of a T2T strategy. Chang et al documented the differences in health outcomes by race at a tertiary academic center, and how use of T2T, and treatment algorithms helped improve outcomes similarly across racial groups.[31] Standardization of T2T and SDM may be an effective tool against implicit racial or cultural bias in patient care. Outcome Measures in Rheumatology (OMERACT) has characterized core domains of SDM.[32] Measurement of these core domains in a trial of T2T and their impact on health outcomes across groups is a compelling area of future study.

Moreover, identified barriers to our current T2T strategy emphasized the challenges with incorporating the T2T approach into the clinic workflow. Contributors include a perceived lack of buy-in, including acceptance and support from clinicians, pediatric rheumatology division directors, divisional leaders, and families. We speculate that some providers and divisional leaders disagree with an SDM approach, whereas others perceive they currently implement it and feel documentation of disease activity and review with families is burdensome or too time-consuming. Since SDM is fundamental to T2T, those who do not support the structured SDM concept will not incorporate T2T into the clinic workflow. The lack of buy-in that serves as a barrier to T2T requires further research for better understanding, such as with qualitative methods.

Also cited as a barrier was the lack of resources, such as having readily available clinical decision aids that are necessary to execute a T2T strategy (eg, an electronic decision support that presents the next best treatment alternatives for a patient based on an algorithm that takes into account treatments that have previously failed them along with clinical factors). To better characterize this issue, next steps may include working with individual centers to map clinic workflow and apply QI tools focused on increasing implementation of T2T.

Limitations of this paper and the consensus conference include the small number of voting members and relative lack of actual patient participation (parents represented their children). Of note, the total number of participants was intentionally constrained by the NGT method. Nevertheless, the invited voting members were representatives from PR-COIN centers who participated in a T2T intervention and were experienced in implementing T2T in a clinic setting, as well as experienced parent stakeholders from these centers. The educational session preceding the voting also informed the voting, with a powerful presentation from a parent advocate on the importance of including what matters most to the patient in treatment considerations. It is possible that this strong opinion was not representative of parents in general, but inclusion of parents in the voting panel discussions added a more balanced perspective.

In conclusion, the consensus process affirmed the importance of including patient goals as part of target setting to inform treatment adjustments in a T2T strategy for JIA. To do so requires the PR-COIN T2T intervention to include a modification of the original T2T task force recommendation that adjusts treatment using a disease activity target alone.[16] This post hoc addition of patient goals as an appropriate target highlights the importance of patient stakeholder involvement in drafting treatment recommendations. Parents and patients bring unique insights and skills to a QI collaborative, making efforts more relevant to the self-identified needs of JIA families. The network approach to T2T will also need to be modified to address other findings from this meeting. Additional research efforts will be required to optimally solicit patient goals and conduct longitudinal monitoring of progress. This raises important measurement challenges, as goals will be heterogeneous and on various individualized measurement scales, perhaps of the patients' own customization. Overall, this paves the way to improve the T2T approach, so that it more effectively achieves the ultimate goal of better outcomes for all patients with JIA.

ACKNOWLEDGMENT

PR-COIN Treat to Target Consensus Meeting activities were funded by PCORI grant RI-PCC-2017 "PCORnet Learning Healthcare System Network Collaborative" (Principal Investigator [PI] Peter Margolis) with subaward to Arthritis Foundation, to support a PARTNERS Learning Health System (LHS) to connect Arthritis Foundation (PI Guy Eakin, PhD) and patient engagement expertise, with PR-COIN (PI Esi M. Morgan, MD, MSCE) and QI expertise, and CARRA (PI Emily von Scheven, MD) and their research expertise to advance patient level outcomes in pediatric rheumatology. Funding of the meeting was approved by PCORI and PARTNERS LHS Executive Committee. We also acknowledge and appreciate the time and participation of speakers at the event (Jon M. Burnham, MD, MSCE, Alessandro Consolaro, MD, PhD, Julia G. Harris, MD, Casper Schoemaker, PhD, Joost Swart, MD, PhD), voting panel members (Supplementary Table 1, available with the online version of this article), facilitator Brian M. Feldman, MD, PhD, pollsters (Tala El Tal, MD, Meghan E. Ryan, DO, Kelsey Petrany), notetaker Janalee Taylor, CNP, and PR-COIN project manager Anne Paul, MBA.

ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

REFERENCES

1. Petty RE, Southwood TR, Manners P, et al. International League

of Associations for Rheumatology classification of juvenile idiopathic arthritis: second revision, Edmonton, 2001. J Rheumatol 2004;31:390-2.
2. Manners PJ, Bower C. Worldwide prevalence of juvenile arthritis – why does it vary so much? J Rheumatol 2002;29:1520-30.
3. Thierry S, Fautrel B, Lemelle I, Guillemin F. Prevalence and incidence of juvenile idiopathic arthritis: a systemic review. Joint Bone Spine 2014;81:112-7.
4. Berthold E, Månsson B, Kahn R. Outcome in juvenile idiopathic arthritis: a population-based study from Sweden. Arthritis Res Ther 2019;21:218.
5. Oen K, Guzman J, Dufault B, et al; Research in Arthritis in Canadian Children emphasizing Outcomes (ReACCh-Out) investigators. Health-related quality of life in an inception cohort of children with juvenile idiopathic arthritis: a longitudinal analysis. Arthritis Care Res 2018;70:134-44.
6. Guzman J, Oen K, Tucker LB, et al; ReACCh-Out investigators. The outcomes of juvenile idiopathic arthritis in children managed with contemporary treatments: results from the ReACCh-Out cohort. Ann Rheum Dis 2015;74:1854-60.
7. Consolaro A, Giancane G, Alongi A, et al; Paediatric Rheumatology International Trials Organisation. Phenotypic variability and disparities in treatment and outcomes of childhood arthritis throughout the world: an observational cohort study. Lancet Child Adolesc Health 2019;3:255-63.
8. Minden K, Niewerth M, Listing J, et al. Long-term outcome in patients with juvenile idiopathic arthritis. Arthritis Rheum 2002;46:2392-401.
9. Chhabra A, Robinson C, Houghton K, et al. Long-term outcomes and disease course of children with juvenile idiopathic arthritis in the ReACCh-Out cohort: a two-centre experience. Rheumatology 2020;59:3727-30.
10. Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN). [Internet. Accessed February 11, 2022.] Available from: https://www.pr-coin.org
11. Kilo CM. A framework for collaborative improvement: lessons from the Institute for Healthcare Improvement's breakthrough series. Qual Manag Health Care 1998,6:1-13.
12. Harris JG, Bingham CA, Morgan EM. Improving care delivery and outcomes in pediatric rheumatic diseases. Curr Opin Rheumatol 2016;28:110-6.
13. Smitherman EA, Consolaro A, Morgan EM. Treat to target in juvenile idiopathic arthritis: challenges and opportunities. Curr Treatment Opt Rheumatol 2018;4:29-43.
14. Ramiro S, Landewé RB, Van Der Heijde D, et al. Is treat-to-target really working in rheumatoid arthritis? A longitudinal analysis of a cohort of patients treated in daily practice (RA BIODAM). Ann Rheum Dis 2020;79:453-9.
15. Stoffer MA, Schoels MM, Smolen JS, et al. Evidence for treating rheumatoid arthritis to target: results of a systematic literature search update. Ann Rheum Dis 2016;75:16-22.
16. Ravelli A, Consolaro A, Horneff G, et al. Treating juvenile idiopathic arthritis to target: recommendations of an international task force. Ann Rheum Dis 2018;77:819-28.
17. Buckley L, Ware E, Kreher G, Wiater L, Mehta J, Burnham J. Improving outcomes using a treat to target approach and clinical decision support in polyarticular juvenile idiopathic arthritis [abstract]. Arthritis Rheumatol 2017;69 (Suppl 10).
18. Brinkman WB, Lipstein EA, Taylor J, et al. Design and implementation of a decision aid for juvenile idiopathic arthritis medication choices. Pediatr Rheumatol Online J 2017;15:48.
19. Harris J, Morgan E, Taylor J, et al. Implementing treat to target approach in the care of juvenile idiopathic arthritis across a network of pediatric rheumatology centers [abstract]. Arthritis Rheumatol 2020;72 (Suppl 4).
20. Zoom. [Internet. Accessed October 22-23, 2020.] Available from: https://zoom.us
21. Schoemaker CG, Wit MPT. Treat-to-target from the patient perspective is bowling for a perfect strike. Arthritis Rheumatol 2021;73:9-11.
22. Swart JF, van Dijkhuizen EHP, Wulffraat NM, de Roock S. Clinical Juvenile Arthritis Disease Activity Score proves to be a useful tool in treat-to-target therapy in juvenile idiopathic arthritis. Ann Rheum Dis 2018;77:336-42.
23. Consolaro A, Giancane G, Schiappapietra B, et al. Clinical outcome measures in juvenile idiopathic arthritis. Pediatr Rheumatology 2016;14:23.
24. Schoemaker CG, Swart JF, Wulffraat NM. Treating juvenile idiopathic arthritis to target: what is the optimal target definition to reach all goals? Pediatr Rheumatol 2020;18:34.
25. Buckley L, Ware E, Kreher G, Wiater L, Mehta J, Burnham JM. Outcome monitoring and clinical decision support in polyarticular juvenile idiopathic arthritis. J Rheumatol 2020;47:273-81.
26. Morgan EM, Munro JE, Horonjeff J, et al. Establishing an updated core domain set for studies in juvenile idiopathic arthritis: a report from the OMERACT 2018 JIA workshop. J Rheumatol 2019;46:1006-13.
27. Delbecq A, Ven A, Gustafson D. Group techniques for program planning: a guide to nominal group and Delphi processes. Glenview, III: Scott, Foresman; 1986.
28. Poll everywhere. [Internet. Accessed February 11, 2022.] Available from: https://www.polleverywhere.com
29. Lipstein EA, Brinkman WB, Britto MT. What is known about parents' treatment decisions? A narrative review of pediatric decision making. Med Decis Mak 2012;32:246-58.
30. El Miedany Y, El Gaafary M, Lotfy H, et al; PRINTO Egypt. Shared decision-making aid for juvenile idiopathic arthritis: moving from informative patient education to interactive critical thinking. Clin Rheumatol 2019;38:3217-25.
31. Chang JC, Xiao R, Burnham JM, Weiss PF. Longitudinal assessment of racial disparities in juvenile idiopathic arthritis disease activity in a treat-to-target intervention. Pediatr Rheumatol Online J 2020;18:88.
32. Toupin-April K, Décary S, de Wit M, et al. Endorsement of the OMERACT core domain set for shared decision making interventions in rheumatology trials: results from a multi-stepped consensus-building approach. Semin Arthritis Rheum 2021; 51:593-600.