







# Transition Guide Dissemination to Foster Patient–Care Team Conversations: A Childhood Arthritis Rheumatology Research Alliance Transition Learning Collaborative Pilot Implementation Study

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**Objective.** Uptake of evidence-informed health care transition processes among pediatric rheumatologists is low despite poor outcomes of transition from pediatric to adult care. We piloted a learning collaborative model to implement transition guides. We dually assessed implementation outcomes and changes in reported patient–care team discussions about transition.

**Methods.** This was a type II hybrid effectiveness-implementation pilot study of transition guide dissemination to patients at least 14 years old with rheumatic conditions across nine pediatric rheumatology centers in the Childhood Arthritis Rheumatology Research Alliance Transition Learning Collaborative. We evaluated implementation outcomes (feasibility, adaptations, and fidelity) and the proportion of patients surveyed that reported having discussions with their care team regarding transfer planning.

**Results.** Six sites were retained through the COVID-19 pandemic (below 70% target). Five out of six sites contributed outcome data (met 80% target) but with substantial heterogeneity in how transition guides were shared (eg, in-person, electronic messages, and posted flyers), and data were collected. The pooled proportion of respondents having discussed transfer planning with their care team was 39% preimplementation ( $n = 239$ ; 95% confidence interval [CI] 32%–46%) and 55% postimplementation ( $n = 864$ ; 95% CI 36%–73%). After implementation, there were significant increases in the likelihood of respondents recalling receiving a transition guide (odds ratio [OR] 2.58, 95% CI 1.35–4.92) and discussing transfer planning (OR 2.14, 95% CI 1.30–3.52), adjusted for age and site of care.

**Conclusion.** Transition guide dissemination is a simple intervention associated with increased awareness among young people with rheumatic conditions and discussions with their care team about transition preparation. The learning collaborative model facilitated identification of several dissemination strategies adaptable to site-specific resources.

## INTRODUCTION

The period of transition from pediatric to adult care for adolescents with chronic diseases is often characterized by

significant delays in routine follow-up, decreased treatment adherence, and increased emergency care use.<sup>1,2</sup> These gaps in care may lead to worsening disease activity.<sup>3</sup> Even with a successful transfer of care, the majority of patients experience

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was interrupted by the COVID-19 pandemic, resulting in several sites withdrawing from the study or changing their adoption plan. The context of these changes and associated site characteristics are detailed in a mixed methods study of adaptations to health system stressors.<sup>17</sup>

**Study population.** The target population for the transition guide intervention included young people ages 14 years and older observed at participating pediatric rheumatology centers for a chronic pediatric rheumatic condition in one of the following self-reported categories: juvenile arthritis, lupus and lupus-related conditions, dermatomyositis, or vasculitis. The age limit aligns with recommendations to begin health care transition discussions between the ages of 12 and 14 years old.<sup>8</sup>

**Intervention.** The evidence-informed practice to be implemented was sharing transition guides with patients and families. A transition guide, sometimes referred to as a transition policy or roadmap, is a document developed by each practice with input from youth and their caregivers that formalizes a consensus around the practice's approach to health care transition, including privacy and consent, as well as age of expected transfer to an adult care provider.<sup>16</sup> The intervention involved systematically sharing a formal transition guide with patients ages 14 years or older and their caregivers to facilitate engagement in discussions about the transition process. The transition guides developed at each participating site were reviewed and approved for readability and appropriateness as per local institutional requirements for patient family education.

**Implementation strategy.** We leveraged a partnered facilitation strategy using the learning collaborative model, which is defined most broadly as the formation of groups of providers or organizations to foster a collaborative learning environment to improve implementation.<sup>12</sup> Facilitation methods included group learning sessions in the form of in-person workshops with invited experts and recorded webinars to teach and share feedback according to the Institute for Healthcare Improvement's collaborative model (Table 1).<sup>18</sup> Audit and feedback was originally planned to occur on a quarterly basis, but given the changes to data collection methods at some sites, run charts were instead provided to site teams after each round of data submission. We also conducted extensive qualitative assessments of local context to identify barriers and facilitators of implementation, the results of which we have previously described.<sup>17</sup>

**Implementation outcomes.** In this pilot study, the implementation outcomes of interest were feasibility, adoption, fidelity, and adaptations, according to the conceptual framework proposed by Proctor et al.<sup>19</sup> Feasibility of enrollment and data collection was defined by retention of at least 70% of sites throughout the implementation period and collection of outcome measures from at least 80% of sites that adopted the intervention. Adoption was defined as the proportion of sites that formalized a transition guide that they intended to employ. Fidelity (adherence to intervention components) was measured by the proportion of patients who recalled receiving a copy of the transition guide in any format. We also conducted a formative evaluation of

**Table 1.** Learning collaborative sessions and format\*

Timeline	Session content	Format
September 2019	Selection of outcome, process, and balancing measures	Phone call, including site updates
November 2019	Components of a process map; drafting site-specific process maps	In-person workshop
December 2019	Assembling a QI team	Phone call, including site updates
January 2020	Introduction to qualitative methods to evaluate implementation and how local contextual factors contribute to success/failure	Phone call, including site updates
February 2020	Nursing perspectives on engaging nonphysician staff	Phone call
March 2020	Guided periodic reflections as an approach for evaluating Plan-Do-Study-Act cycles	Phone call
May 2020	Managing behavior change	Virtual interactive webinar (invited guest speaker)
June 2020	Use of EHR tools to improve reliability of measurement	Video conference, including site updates
July 2020	Patient perspectives on telehealth and transition processes	Virtual panel of young adults with Q&A
October–November 2020	Qualitative analysis of barriers to implementation and local adaptations	Semistructured interviews with representatives from individual sites
December 2020	Use of run charts to track performance	Video conference, including site updates
January–April 2021	Individualized guidance to troubleshoot problems	Calls with individual sites
May 2021	Site updates only	Video conference
June–October 2021	Individualized guidance to troubleshoot problems	Calls with individual sites
November 2021	Site updates only	Video conference

\*EHR, electronic health record; Q&A, question and answer; QI, quality improvement.

adaptations to local transition guide dissemination in relation to effectiveness outcomes, as well as unanticipated costs or problems.

**Effectiveness (client service) outcomes.** Improved patient understanding and awareness of the need to transition was defined as an increase in the proportion of patients reporting discussing transition with their pediatric rheumatology care team. Patient-reported effectiveness and fidelity measures were collected from either a random sample or convenience sample of patients at each site using a brief, anonymous transition awareness survey (Supplemental Material). Random sampling included surveying all eligible patients seen in clinic during randomly selected weeks each month or quarter, whereas convenience samples could include mass electronic health record (EHR) communications or surveys collected in clinic.

**Analysis.** Because of the impact of the COVID-19 pandemic, which resulted in varying degrees of delays and different local adaptations to the data collection strategy at each site, we were unable to conduct the prespecified time series analysis and converted to a before and after study design. As such, the calendar dates defining preimplementation and postimplementation periods and number of sampling time points could differ across sites. Chi-square tests were used to evaluate site-specific preimplementation versus postimplementation differences in the proportions of respondents who reported (1) having a discussion about transition with their care team or (2) receiving a copy of the transition guide. Pooled proportions across all sites with exact confidence intervals (CIs) were computed using a random-effects model with Freeman-Tukey double arcsine transformation.<sup>20</sup>

Overall adjusted changes in the two patient-reported measures across the learning collaborative were estimated using separate mixed-effects logistic regression with an indicator variable for postimplementation versus preimplementation period and random effects for site of care. Covariates (age, sex, and disease category) were considered in the models and retained if model fit improved based on likelihood ratio tests or if there was evidence of confounding based on a change in odds ratio (OR) for postimplementation versus preimplementation period by 15% or more. Sample size was determined based on practical considerations surrounding sampling methods as described above, as well as the number of interested sites with transition champions. All statistical analyses were conducted using STATA version 16.0 with a two-sided significance level of 0.05.

## RESULTS

### Characteristics of the recipient population.

Characteristics of the population of young people for which the intervention was intended and responded to the transition surveys are summarized in Table 2. Of 1,399 surveys completed by patients, 1,123 listed a qualifying rheumatic condition, and 1,103 collected during active preimplementation or postimplementation periods were analyzed. In total, there were 239 respondents from five sites during the site-specific preimplementation (baseline) periods, of which the majority (46%) listed juvenile arthritis as their primary rheumatologic diagnosis, followed by lupus or lupus-related conditions (30%). Respondents were more commonly female (72%) and 18 years of age or older (43%). There were 864 respondents during the postimplementation periods. Compared to respondents during the baseline period, a larger

**Table 2.** Respondent demographics preimplementation and postimplementation of transition guides

Disease category	Preimplementation (n = 239), n (%)	Postimplementation (n = 864), n (%)	P value <sup>a</sup>
Juvenile arthritis	111 (46)	610 (71)	<0.01
Lupus-related	72 (30)	179 (21)	
Vasculitis	49 (21)	23 (3)	
Juvenile myositis	7 (3)	52 (6)	
Age category			<0.01
14–15 y	50 (21)	324 (38)	
16–17 y	86 (36)	359 (42)	
≥18 y	103 (43)	181 (21)	
Gender			0.43
Male	66 (28)	228 (26)	
Female	171 (72)	633 (73)	
Nonbinary or prefer not to answer	2 (1)	3 (0)	
Site			-
1	27 (11)	18 (2)	
2	64 (27)	170 (20)	
4	71 (30)	30 (3)	
5	8 (3)	22 (3)	
6	69 (29)	624 (72)	

<sup>a</sup>Chi-square tests or Fisher exact tests for n < 5.

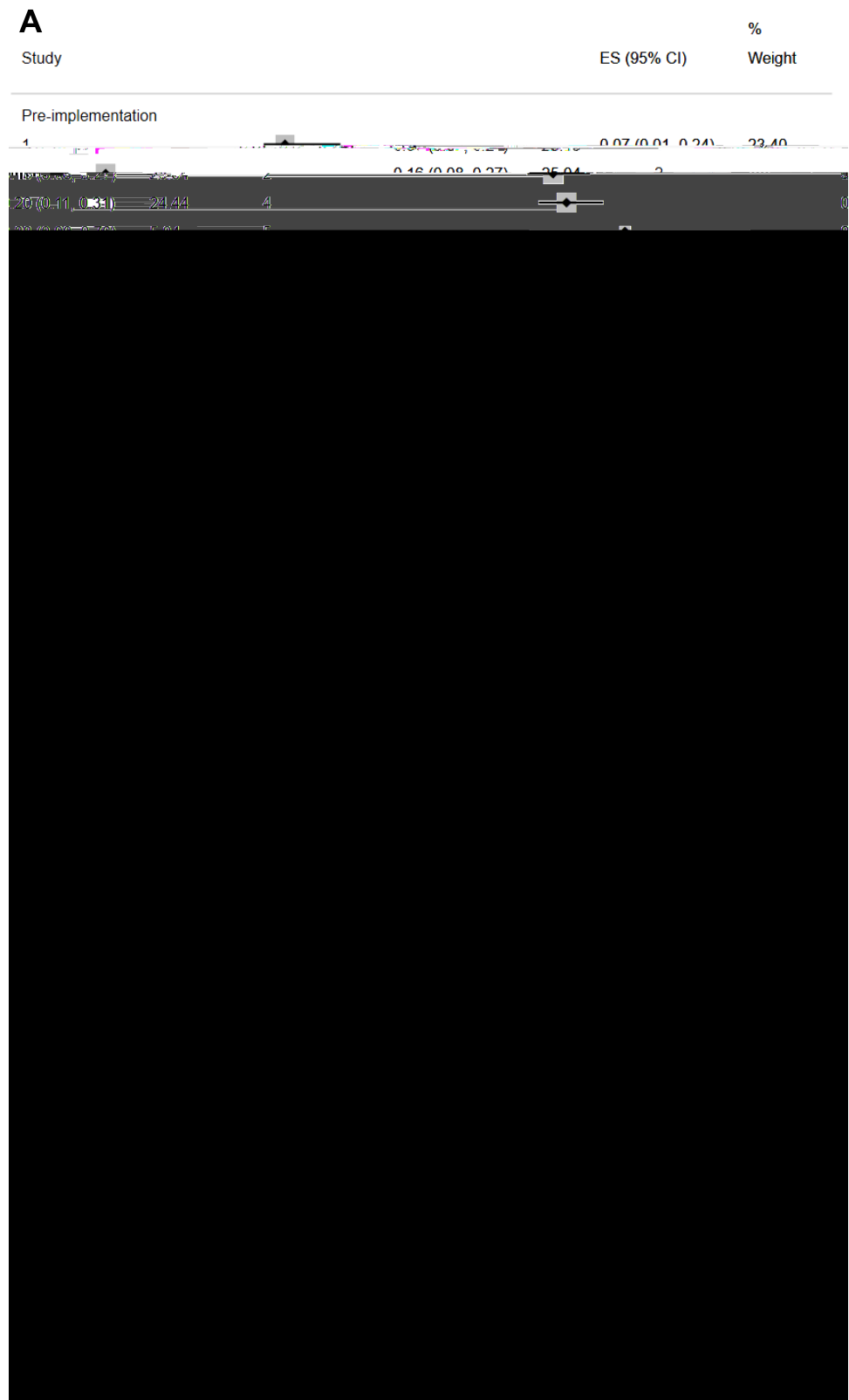
proportion of postimplantation respondents had juvenile arthri-

**Table 3.** Local contextual factors and adaptations\*

Site	Transition team	Guide format	Dissemination strategy	Formal staff training	Process measured	Patient outcome data collection	Effectiveness of dissemination strategy
1	Physician champion	Paper	Printed copy distributed during clinic visits by provider/RN with synchronous counseling; no previsit planning	None	No	Paper survey distributed in clinic by provider/RN	Significant increases in reported receipt of transition guide (7%–50%, $P < 0.01$ ) and transfer discussion with care team (37%–72%, $P = 0.02$ )
2	Physician <sup>a</sup> and RN <sup>a</sup> champion, social work	Paper, then electronic	Printed copy initially distributed during clinic visits by RN. Rapidly shifted to patient portal message sent monthly by nursing to patients with upcoming visits in an EHR-enabled transition registry	Quarterly QI meeting <sup>c</sup> with all clinic providers to review process and outcome metrics	Yes; provider EHR template	Monthly patient portal message with electronic survey link sent to patients seen in clinic that month by RN	Significant increases in reported receipt of transition guide (16%–60%, $P < 0.01$ ) and transfer discussion with care team (38%–58%, $P < 0.01$ )
3 <sup>b</sup>	Physician champion	Paper	Printed copy distributed in clinic by provider with previsit planning	None	No	Paper survey distributed in clinic by provider	No applicable data (site withdrew)
4	Physician champion, social work, RNs	Electronic only	Annual mass patient portal message with downloadable transition guide attachment sent by SW	Quarterly transfer planning meeting <sup>c</sup> with providers and SW	Yes; templated documentation by social work in EHR specialty comments	Mass patient portal messages with electronic survey link managed by SW	Numerical but not statistically significant increases in reported receipt of transition guide (20%–33%) and transfer discussions (49%–63%)
5	Physician champion, dedicated transition clinic	Electronic and paper	Tablet provided at check-in and QR code on flyer posted in clinic rooms	None	Yes; linked to REDCap and provider EHR note template	Patients acknowledge understanding and review of transition guide (survey)	Low response rates precluded site-specific evaluation of intervention effectiveness
6	Physician <sup>a</sup> and RN champions	Electronic and paper	Automated EHR-enabled alert for RNs to print transition guide	One-time RN training led by champions; one-time re-training of RNs	Yes; nursing note in EHR problem list and after-visit summary	Electronic survey via tablet distributed by front desk staff	No change in reported rates of transition guide receipt (29% pre and post) or transfer discussions (32%–30%)

\*EHR, electronic health record; QI, quality improvement; RN, registered nurse; SW, social worker.

<sup>a</sup>Loss of physician or nursing (RN) champion(s) during implementation period.<sup>b</sup>Withdrew following baseline data collection and not included in analysis.<sup>c</sup>Project-specific training conducted within pre-existing infrastructure for practice-level quality improvement efforts that include clinic leadership.



**Figure 2.** Pooled estimates with 95% confidence intervals of the proportion of survey respondents reporting (1) having received a copy of the transition guide or (2) having had a discussion with their care team regarding transfer planning during the baseline preimplementation period and the postimplementation period for each site.

**Table 4.** Likelihood of recalling transition guide or transfer discussions increased after implementation\*

	Receive transition guide			Discuss transition with care team		
	OR	95% CI	P value	OR	95% CI	P value
Implementation period						
Preimplementation	(reference)			(reference)		
Postimplementation	2.58	1.35–4.92	<0.01	2.14	1.3–3.52	<0.01
Age category						
14–15 y	(reference)			(reference)		
16–17 y	0.81	0.59–1.1	0.18	2.26	1.62–3.15	<0.01
≥18 y	1.36	0.94–1.96	0.11	13.26	8.72–20.16	<0.01

\*Associations between implementation of transition guides (postimplementation versus preimplementation period for each site) and likelihood of transition-age patients recalling (1) receiving a transition guide or (2) discussing transfer timing with their care team. Estimates are from separate mixed-effects logistic regression with random effects for site of care ( $n = 1,098$ , five sites), adjusted for age. Gender and disease category did not meet criteria for inclusion in adjusted models. CI, confidence interval; OR, odds ratio.

Statistically significant, unadjusted site-specific increases in patient-reported transition guide receipt and discussion of transfer timing were observed at two out of five sites (Supplemental Table 2). Run charts with data collection time points and calendar periods for each site are shown in Supplemental Figures 1 and 2. One of the successful sites had an existing practice-level quality improvement infrastructure for provider training and used substantial information technology (IT) resources to support both transition guide dissemination and data collection that was temporally adjacent to clinical encounters (site 2). In contrast, the other successful site had no formal staff training procedures and used no IT resources save for routine clinic business reports (site 1). Of sites that did not achieve significant site-specific improvements in either outcome, one used automated EHR-enabled reminders that were intended to trigger transition guide distribution and education by clinic nursing staff but were often-times overlooked (site 6). Another (site 4) used a mass, annual EHR-based distribution that, unlike site 2, was asynchronous with clinical encounters, and the last (site 5) used flyers posted within clinic rooms (Table 3).

Unanticipated costs included patient or caregiver anxiety caused by misunderstanding the purpose of the transition guides when they were distributed asynchronously with clinical encounters. In spite of the inclusion of an explanatory message alongside the transition guides, a few families responded with alarmed messages to their providers, asking whether they were going to be allowed to continue care with their pediatric rheumatologist or would be expected to transfer to adult care immediately. Although this was a rare occurrence, it was not completely mitigated by the prefacing statements included with the transition guides. Similar problems were not observed at the site where providers distributed paper copies directly to their patients during clinical visits. Opportunity costs with respect to time dedicated by clinic staff was context specific. Sharing paper copies of transition guides was estimated to add three to five minutes to a clinical visit. Although mass electronic distribution removed the burden of extra time and staffing during clinical encounters, staff time was

still required to properly identify the target audience and push the communications out.

## DISCUSSION

Transition guides are a simple and inexpensive intervention with the potential to increase awareness of health care transition among young people with childhood-onset rheumatic diseases and their families.<sup>21</sup> This hybrid effectiveness-implementation pilot study demonstrated statistically significant increases in patient-reported transfer planning discussions with their rheumatology care team following dissemination of transition guides. Our findings suggest that transition guide dissemination is associated with increased transition awareness among young people in pediatric rheumatology clinics and fosters discussion of the transition process with their care teams. This work adds to the literature supporting the use of structured transition processes to promote transition preparation.<sup>22,23</sup> We also establish the specific use of sharing transition guides as a single process, which has otherwise only been demonstrated to improve outcomes in the context of complex, multicomponent interventions in primary care,<sup>24–26</sup> pediatric rheumatology,<sup>27</sup> or other chronic complex care settings.<sup>22,28</sup> In the only single-center study of an isolated transition policy intervention conducted over a similar time period, paper distribution in a pediatric rheumatology clinic was not associated with significant longitudinal increases in transition preparation scores.<sup>29</sup> In our study, we observed age-adjusted, population-level increases in transfer planning discussions using a learning collaborative to facilitate implementation of transition guides, albeit with substantial site-level variability in both contextual factors and outcomes.

With regard to the feasibility of implementing structured transition processes via creation of a learning collaborative, this work illustrated significant barriers faced by rheumatology care teams in real-world settings, which were further exacerbated by stresses placed on care teams during the COVID-19 pandemic.<sup>17</sup> Among the 10 sites that initially indicated intent to participate in the



learning collaborative, 9 began participation, 3 dropped out because of stresses attributed to the pandemic, and 1 dropped out because of inadequate staffing to continue data collection. At each site that successfully completed the study, the availability of nonphysician transition support was critical as part of the transition team and/or to provide support in transition guide distribution and outcome data collection. It is noteworthy that among the six sites that began study participation, the one site that lacked nonphysician support was unable to complete the study.

In addition, we identified other contextual factors that may have moderated the effect of the learning collaborative as the primary implementation facilitation strategy, including existing practice-level infrastructure for quality improvement and IT resources. Some sites had formalized practice improvement meetings involving providers within which provider training could be embedded. Conducting ongoing training in an evidence-based practice is itself a discrete implementation strategy and could impact the frequency, content, or quality of patient and provider discussions regarding transition.<sup>12</sup> As a result, whether patients recall having discussions with their care team about transition is likely modified by provider training and the organizational structures that support ongoing training. Second, although IT resources were previously identified as important facilitators of maintaining implementation momentum,<sup>17</sup> they were neither necessary nor sufficient to achieve significant improvements in patient awareness. However, how sites leveraged their local EHR to support implementation (eg, patient identification, automated reminders, and distribution of transition guides) is a potential modifier. In practice, automated reminders were often missed and failed to result in higher rates of patient-reported transfer planning discussions. Although mass EHR-enabled distribution of transition guides that occurred asynchronously with clinical encounters generated follow-up interactions between patients and the care team, few families reported receiving the guide when it was distributed in this way. In contrast, EHR-enabled transition guide distribution at a time adjacent to a clinical visit associated with better patient-reported outcomes, possibly because of increased salience or the higher likelihood of being followed up with care team communication. Limited time and multiple competing demands during clinical visits may necessitate greater consideration of asynchronous delivery in the design of educational interventions related to health care transition. Lastly, sites differed with respect to organizational commitment and team characteristics, the impact of which will need to be assessed in larger studies.

A strength of this study was the opportunity for each site to choose the dissemination approach that was most appropriate for their practice's specific context, needs, and preferences. Through this approach, we aimed to maximize the feasibility of the transition guide dissemination intervention and associated data collection and to increase the probability that sites would develop sustainable processes that could be implemented

continuously even after conclusion of the study. This approach also allowed us to conduct formative evaluations of different adaptations, including both in-person distribution of paper transition guides and asynchronous electronic dissemination via the electronic medical record. In addition, the learning collaborative structure helped to advance the work by allowing sites to learn from each other and troubleshoot barriers during learning collaborative meetings. One of the theorized mechanisms of learning collaboratives includes sharing experiences across sites and strengthening interorganizational learning.<sup>30,31</sup> However, the flexibility of our approach also necessitated heterogeneity in the delivery of the core components of the transition guide intervention, which is a notable weakness that warrants cautious interpretation of the pooled results. There is a natural tension between implementation fidelity and adaptation, and the ideal balance between adhering strictly to proven-effective programs and meeting the needs of real-world communities remains unclear.<sup>32</sup> We only measured one aspect of implementation fidelity—the extent to which patients reported receiving the intervention. However, there are many other components to fidelity that need to be considered as implementation outcomes in future trials, including quality of delivery and patient enactment, and their potential moderating effects.<sup>19,33,34</sup>

It is important to consider potential unintended harms attributable to transition guide distribution. First, depending on the methodology employed, in-person dissemination of transition guides has the potential to be time consuming for staff. This use of time must be weighed against other important tasks, such as disease education, adherence discussions, contraceptive counseling, and mental health screening.<sup>35–38</sup> Although our study did not specifically measure the time needed to implement the intervention, it is important to consider these opportunity costs.<sup>39</sup> Second, at sites that mass distributed transition guides via the EHR, it was noted that a small number of families were confused, or even alarmed, upon receiving the transition guide outside of the context of a clinical encounter. Prefacing statements explaining the purpose of the transition guide did not completely mitigate the risk of families mistaking the transition guide for an indication that they were being asked to transfer to adult care imminently. Therefore, the higher efficiency of asynchronous electronic distribution of transition guides must be weighed against potential confusion of the recipients.

There are several important limitations to acknowledge. This was an unrandomized, unblinded intervention spanning several years. Both secular trends as well as time-dependent effects because of varying site-specific delays and changing workflows during the pandemic could theoretically have influenced the outcomes. Because this was a pilot study, we measured relatively few implementation outcomes. Penetration, defined as the proportion of the target population that received the intervention,<sup>19,40</sup> could only be assessed indirectly through patient surveys, which is subject to both recall and sampling bias.

Future work will need to focus on additional implementation outcomes, including penetration, reach, and sustainment. Lastly, the relatively low site retention rate and adaptations to the data collection methods at some sites precluded use of a quasi-experimental analytic approach. Therefore, our results are purely observational, and no causal inferences can be made. At the same time, the characterization of these various adaptations is instructive and can serve as a practical guide to future quality improvement efforts or implementation studies involving informational interventions in pediatric rheumatology practices with differing resources.

In summary, this work demonstrated that systematic transition guide distribution may be a practicable care process to increase awareness among patients and their caregivers of the need for health care transition and to foster transition preparation conversations between patients in pediatric rheumatology and their care teams, especially when the dissemination method is adaptable to site-specific context. As our study focused on a single care process, more work is needed to generate evidence about the best strategies to implement multicomponent, often resource-intensive, evidence-based practices in pediatric rheumatology. Future directions will focus on refining the learning collaborative approach and mapping additional implementation strategies to incorporate additional components of the Six Core Elements of health care transition into routine pediatric rheumatology practice.

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## AUTHOR CONTRIBUTIONS

All authors contributed to at least one of the following manuscript preparation roles: conceptualization AND/OR methodology, software, investigation, formal analysis, data curation, visualization, and validation AND drafting or reviewing/editing the final draft. As corresponding author, Dr Chang confirms that all authors have provided the final approval of the version to be published, and takes responsibility for the affirmations regarding article submission (eg, not under consideration by another journal), the integrity of the data presented, and the statements regarding compliance with institutional review board/Helsinki Declaration requirements.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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