Title

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Enhancing Care Partnerships Using a Rheumatology Dashboard: Bringing Together What Matters Most to Both Patients and Clinicians

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Objective. Dashboards can support person-centered care by helping people partner with their clinicians to coproduce care based on preferences, shared decision-making, and evidence-based treatments. We engaged caregivers of children with juvenile idiopathic arthritis (JIA), adults with rheumatoid arthritis (RA), and clinicians in a pilot study to assess their experiences and the utility and impact of an electronic previsit questionnaire and point-of-care dashboard to support coproduction of rheumatology care.

Methods. We employed a mixed-methods design to assess users' perceptions of a customized electronic health record rheumatology module at four pediatric rheumatology practices and two adult rheumatology practices. We surveyed a convenience sample of caregivers of children with JIA (n = 113), adults with RA (n = 116), and clinicians (n = 12). We conducted semistructured interviews with 13 caregivers and patients and six care teams. Experiences were evaluated using descriptive statistics and thematic analyses.

Results. Caregivers of children with JIA and adults with RA reported the dashboards were useful during discussions (88%) and helped them talk about what mattered most (82%), make health care decisions (83%), and create a treatment plan (77%). Clinicians provided similar feedback. Two-thirds (67%) of caregivers and adults and 55% of clinicians would recommend the dashboard to peers. System usability scores (77.1 ± 15.6) were above average. Dashboards helped users make sense of health information, communicate more effectively, and make decisions. Improvements to the dashboards and workflows could enhance patient self-management and clinician efficiency.

Conclusion. Visual point-of-care dashboards can support caregivers, patients, and clinicians to coproduce rheumatology care. Findings demonstrate a need to spread and scale for broader benefit and impact.

INTRODUCTION

Millions of people in the United States live with serious rheumatologic conditions that can cause pain, functional limitations, and diminished quality of life (1,2). Engaging people in their care can lead to better health and outcomes (3), yet people with arthritis and their caregivers often view their disease and goals differently from clinicians (4). Enhancing the partnership between clinicians and people with arthritis and their caregivers can ensure that decisions are made together based on meaningful outcomes. Each party brings their own knowledge and expertise to the partnership, and each has values, goals, preferences, and their own understanding of clinical evidence and treatment options (5,6). Inviting and integrating these unique strengths to coproduce care by coassessing health status and codeciding next steps in the care and treatment plan (7) may enhance care delivery and health outcomes for people with arthritis.

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SIGNIFICANCE & INNOVATIONS

- It is feasible to collect and display electronic patient-reported outcomes (PROs) alongside clinical data within a visual dashboard native to the electronic health record (EHR).
- A visual dashboard of PROs and clinical data has value to people with arthritis and their clinicians. It can support better understanding of health information, shared decision-making, and coproduction of health care services.
- A point-of-care dashboard that is embedded within the EHR is useful to clinicians. Refinement of workflows can further enhance usability.

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Previous research has shown that coproduction of health care services may be supported by visual dashboards that bring together information that matters both to patients and their caregivers and to clinicians, serving as a guide for discussion and shared decision-making during a clinical encounter (8,9). Such visual dashboards can display an individual's current goals and concerns alongside real-time longitudinal patient-reported outcomes (PROs), key clinical data, and treatments or medications. Design criteria and prototypes of rheumatology dashboards have been developed to support children with juvenile idiopathic arthritis (JIA) and their caregivers (10,11) and adults with rheumatoid arthritis (RA) (12,13). Dashboards have served as an important element of the Swedish Rheumatology Quality Registry (14).

Despite the potential of dashboards, they often exist outside the electronic health record (EHR) (15–17) and are limited by lack of real-time data (8,9). They can create burden for clinicians to navigate multiple systems to view disparate information and for patients to access multiple systems at a time when medical organizations are optimizing EHR patient portals. Evidence suggests that most currently available e-health applications (apps) are not easily interfaced with a local EHR using HL7 FHIR (Health Level 7 - Fast Healthcare Interoperability Resources) standards (18) and can be difficult to scale and implement (19) without further standardization. Although the 21st Century Cures Act (20) was enacted to overcome these barriers, currently available common data elements focus on allergies, clinical notes, demographics, medications, problem lists, test results, team members, and vital signs, among others, but often do not include patient-reported data (21).

Little is known about the potential feasibility or utility of using tools embedded within the EHR to enhance partnerships and support shared decision-making between people with arthritis and their clinicians. This pilot study aims to identify perceptions of caregivers of children with JIA, adults with RA, and clinicians regarding experience, utility, impact, and challenges of using electronic previsit questionnaires (PVQs) and visual dashboards to support coproduction of rheumatology care.

MATERIALS AND METHODS

Participating sites. We convened six academic rheumatology practices (four pediatric, two adult) to identify, develop, and test behavioral and technological changes at the point of care that could support coproduction of health care services among children with JIA and their caregivers, adults with RA, and clinicians.

Modification of EHR rheumatology module. Each clinical team conducted EHR workflow analyses and developed site-specific enhancements to pediatric and adult rheumatology modules native to the Epic EHR. Teams engaged in a human-centered design process to understand current care contexts and user experiences and to achieve consensus on a minimum set of PROs and clinical data elements (11).

Biweekly collaborative learning calls were held between the research group, pediatric and adult teams, and patient and caregiver partners. Discussions focused on identifying and developing modifications to the modules and implementing the PVQ and dashboard. Modifications were designed 1) to improve communication of patients' goals and preferences, of changes in health outcomes over time, and of impact of treatment regimens on key clinical and PRO data and 2) to support shared decision-making on treatment options. Technical support to modify the rheumatology module was provided by site-level EHR analysts. The research team provided support for small-scale testing using quality improvement methodologies (22).

Native rheumatology module components include a body diagram (homunculus), tender joint count, swollen joint count, and disease activity (Table 1). Enhancements include the addition of PROs from the PVQ, free-text responses, and standardized data binding to align with clinical research and improvement registries. PVQ questions were written at a fourth- to eighth-grade reading level and were available in Spanish at one site. The dashboards longitudinally display these data, along with treatments or medications, on a timeline (Figure 1A and B).

Implementation. Caregivers of children with JIA and adults with RA were prompted via their EHR patient portal to complete a PVQ approximately 1 week prior to their scheduled clinic visit as part of routine care. Patient access to the EHR portal varied across sites, ranging from 60% to 90%. Individuals who did not complete the PVQ prior to arrival could complete it in the clinic waiting area or with support of a care team member at some sites. PVQ responses were immediately visible within the dashboard. Clinicians entered a limited set of data into the dashboard via the EHR during the clinic visit (eg, tender and swollen joint counts, physician global assessment).

Teams focused on optimizing processes and mitigating barriers to support effective use of the dashboard at the point of care. Areas of focus included the following: 1) increasing the

Table 1. Epic rheumatology module native functionality and enhancements to support coproduction of health care services during a clinic visit

Native module functionality	Pediatric module enhancements	Adult module enhancements
Homunculus: body diagram to document joint assessment; can manually enter patient and provider global disease activity scores and inflammatory marker values (ESR and CRP)	Autopopulated patient global disease activity assessment informed by previsit questionnaire response	No adaptations required
Patient timeline: displays disease activity scores; total tender and swollen joint counts over time	Enhanced patient timeline data elements included the following: 1) PROs of pain and PROMIS pain interference, upper extremity function, and mobility using standardized data binding to align with CARRA and PR-COIN (30) data elements and to autopopulate within PR-COIN forms; 2) clinical data, including JADAS; and 3) current and past medications	Enhanced patient timeline data elements included the following: 1) RAPID3, a composite PRO of function, pain, and patient global assessment; 2) clinical data, including CDAI and tender and swollen joint counts; and 3) current and past medications
Other	"What questions or concerns do you have for today's visit?" Medication adherence, Medication side effects	"What's on my mind for today's visit?"

Abbreviations: CARRA, Childhood Arthritis and Rheumatology Research Alliance; CDAI, Clinical Disease Activity Index; CRP, C-reactive protein; ESR, erythrocyte sedimentation rate; JADAS, Juvenile Arthritis Disease Activity Score; PR-COIN, Pediatric Rheumatology Care and Outcomes Improvement Network; PRO, patient-reported outcome; PROMIS, Patient-Reported Outcome Measurement Information Systems; RAPID3, Routine Assessment of Patient Index Data.

percentage of patients with a patient portal account, 2) ensuring that adults with RA and caregivers of children with JIA completed the PVQ in advance of the visit via their patient portal to minimize disruptions in workflow during the clinic visit, 3) using and reviewing the dashboard during the clinic visit, and 4) maximizing EHR functionality to optimize documentation and integration with registries to support research and quality improvement. A small group of clinicians, caregivers of children with JIA, and adults with RA codesigned educational materials to support use of the PVQ and dashboard (Supplementary Materials).

Evaluation and data collection. A formative evaluation was conducted to evaluate experience, utility, impact, and challenges of the PVQ and dashboard, following methods used in similar initiatives (8,9).

Anonymous surveys. A convenience sample of patients who completed the PVQ received an invitation from their clinician between January 2020 and September 2021 to complete an anonymous paper or online postvisit survey addressing the following: use of the PVQ and dashboard; likelihood of recommending the dashboard to a peer, as measured by a 0 to 10 rating on the Net Promoter Score (NPS), in which 0 = not at all likely, and 10 = extremely likely (23); characteristics of the care experience, including utility of the dashboard, extent to which primary concerns or goals were addressed, and perceived shared decision-making, as measured by the brief 3-item collaboRATE scale (24); and demographic and clinical characteristics. Confidence to manage disease was measured using a 0 to 10 ordinal scale, with higher scores indicating higher confidence (25). Health literacy was measured using a five-point Likert scale.

Clinicians participating in the initiative completed an electronic survey approximately 9 months after initiating use of the dashboard. The survey addressed use and utility of the PVQ and dashboard; likelihood of recommending the dashboard to a peer, as measured by the NPS (23); usability of the dashboard, as measured by the System Usability Scale (SUS) (26); utility of the dashboard; and demographic and caseload characteristics. Surveys were collected between January and May 2021.

Semistructured interviews. Caregivers of children with JIA and adults with RA were recruited by clinicians to participate in semistructured interviews. Interviews addressed all core questions from the interview guide, including partnering with clinicians, utility of and experience with using the dashboard, and advice for others. Each clinical team was invited to participate in a semistructured interview. In addition to core questions, clinical team interviews addressed strategies for integrating the PVQ and dashboard into workflows and supports and barriers for use. Interviews were conducted by an experienced qualitative researcher (ADVC) between February and April 2021.

Analysis. Data were summarized with descriptive statistics. The NPS was calculated as the proportion of promoters of the dashboard (score of 9-10) minus the proportion of detractors (score of 0-6) (27). The SUS was calculated using an established scoring framework (26) in which a score of 68 or higher is considered above average. High shared decision-making was defined as a top-box score (score of 9) on each of the three collaboRATE questions (24).

Relationships between categorical variables were determined with chi-square tests and, as appropriate, Fisher's exact

A. Adult dashboard
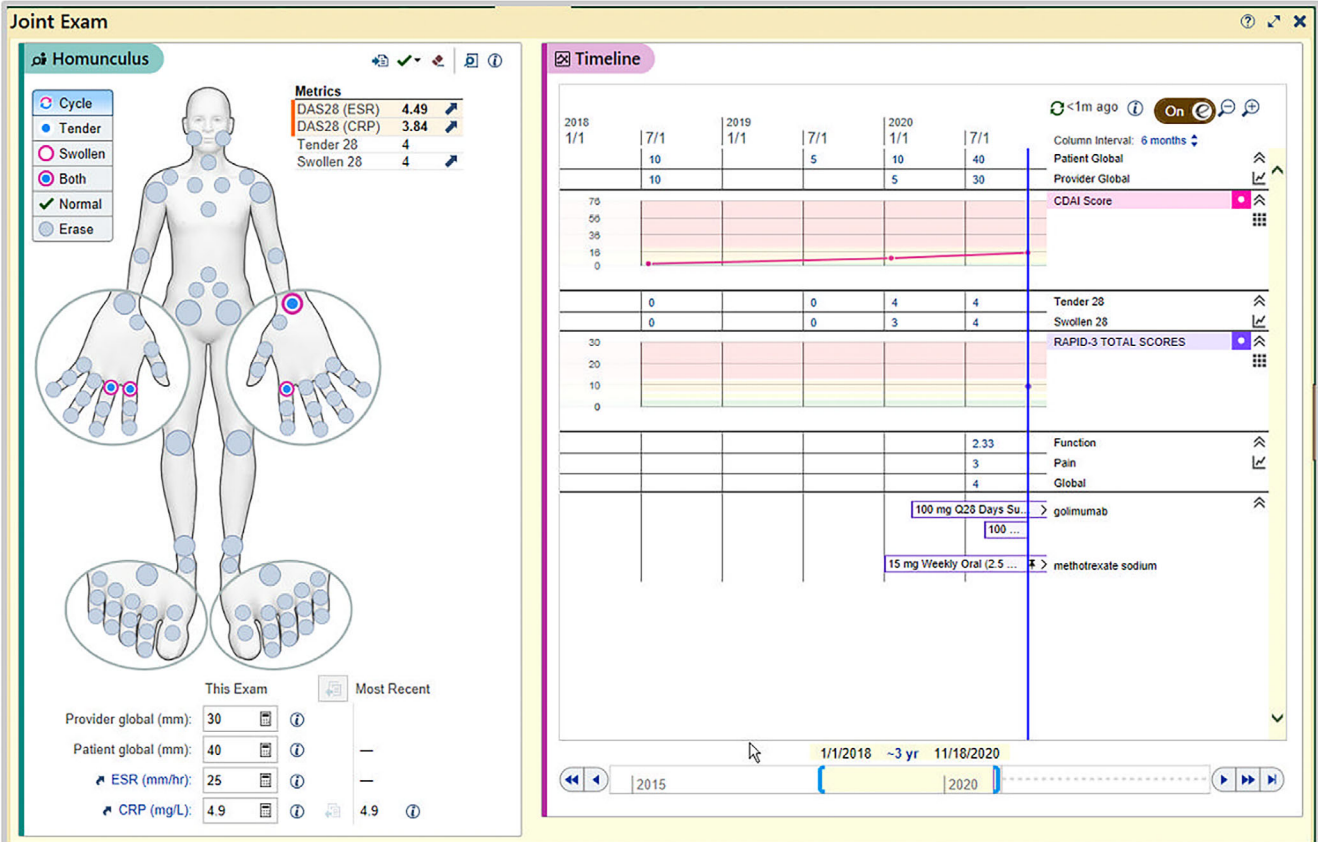
B. Pediatric dashboard
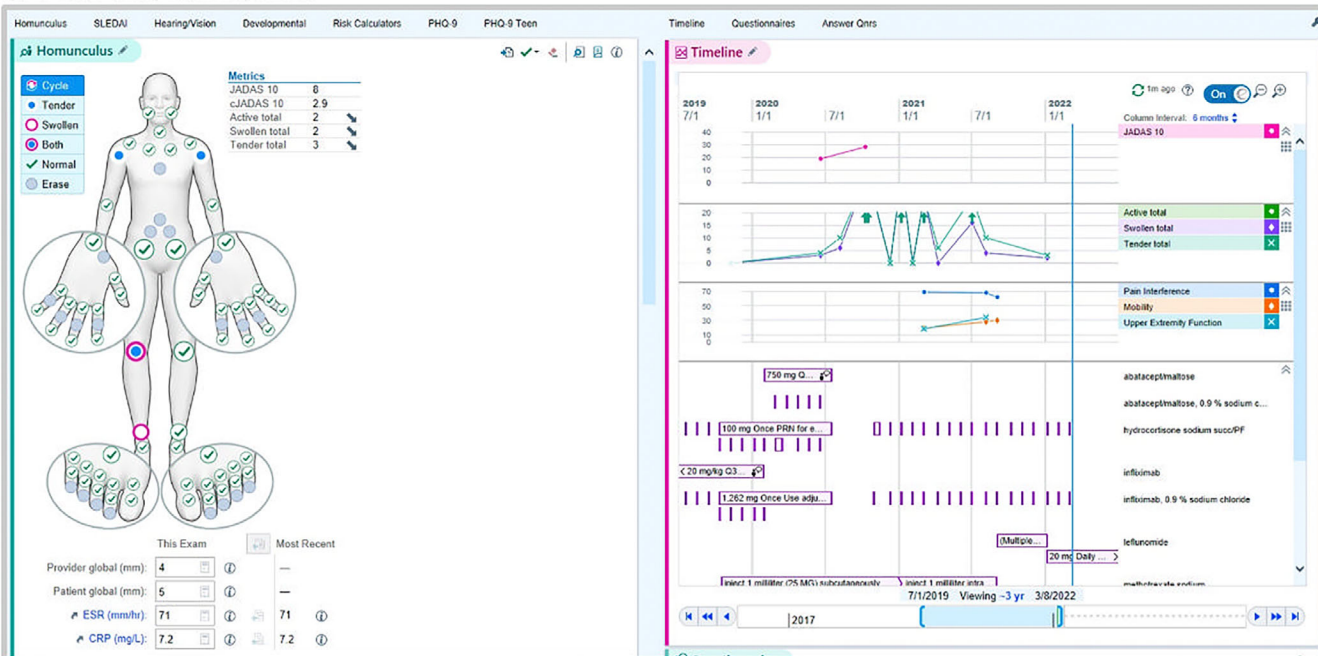
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Figure 1. Dashboard screenshots. **A**, Adult rheumatology dashboard. **B**, Pediatric rheumatology dashboard. Native rheumatology module components include a body diagram (homunculus), tender joint count, swollen joint count, and disease activity on the left-hand panels. The dashboards longitudinally display these data, along with treatments or medications, on a timeline (right-hand panels). Abbreviations: CDAI, Clinical Disease Activity Index; cJADAS, Clinical Juvenile Arthritis Disease Activity Score; CRP, C-reactive protein; DAS28: Disease Activity Score-28; ESR, erythrocyte sedimentation rate; JADAS-10, Juvenile Arthritis Disease Activity Score; RAPID-3, Routine Assessment of Patient Index Data.

tests to account for small sample sizes. We explored variation in response patterns between respondent groups. High and low confidence to control and manage health problems was defined as scores of 7 to 10 and 6 or lower, respectively (25). Health literacy was defined as marginal or limited (not at all, a little bit, or somewhat confident) and high (quite a bit or extremely confident) in self-assessed ability to fill out health forms. A *P* value threshold of less than 0.05 was used to identify significant differences using two-sided significance tests. Quantitative analyses were conducted using SPSS version 26 (IBM SPSS Statistics, IBM Corp).

Qualitative data were analyzed with thematic analysis. Interview transcripts were coded by a primary reviewer (JA), with a secondary reviewer (ADVC) coding a 20% sample of transcripts. All qualitative data from surveys were coded by two reviewers (ADVC and JA). Discrepancies were identified and discussed between reviewers to reach consensus. Qualitative analyses were conducted using Atlas.ti (version 9.1.3, ATLAS.ti Scientific Software Development GmbH).

The study was approved by the Dartmouth College Committee for the Protection of Human Subjects (study: 31341). Certain sites applied for and received institutional review board waivers as deemed necessary by local site requirements.

RESULTS

Participants. Rheumatology practices were located in the mid-Atlantic (n = 2), Northeast (n = 1), Southern (n = 1), and Western (n = 2) United States. All were in academic medical centers. Four were pediatric practices (seven clinicians), and two were adult practices (five clinicians). A median of two (range 1-3) clinicians participated per site. Clinicians included physicians

(n = 10), a physician assistant (n = 1), and an advanced practice nurse (n = 1). Most pediatric clinicians (n = 4) and all adult clinicians (n = 5) indicated that 26% to 50% of their caseload consisted of children with JIA or adults with RA, respectively.

Postvisit surveys were completed by 113 caregivers of children with JIA and 116 adults with RA (Table 2). Most respondents were female (82%), spoke English as their primary language (93%), and had graduated from college (60%). Most were confident in their ability to manage and control most health problems (87%) and had high health literacy (93%). There were no differences in these characteristics between caregivers of children with JIA and adults with RA. Two-fifths of children with JIA (n = 44) had one or more nonroutine rheumatologic visits in the past year. One-quarter of adults with RA (n = 27) considered their disease to be moderately or very active, with disruptive to severe symptoms.

Semistructured interviews were completed with six caregivers of children with JIA, one adult with JIA, and six adults with RA (median: 28 minutes; range: 20-34 minutes) and with clinicians from each of the six care teams (median length: 52 minutes; range: 40-58 minutes).

Experience and use of the PVQ and dashboards. Three-quarters of survey respondents submitted a PVQ prior to arriving at their appointment. Most (97%) reported that the PVQ was "easy" or "very easy" to complete. Most respondents (90%) reported that their clinicians shared the dashboard during the visit. Four-fifths reported discussing PVQ responses with their clinicians. Nearly all (93%) reported that their primary concerns or goals were fully addressed by their clinicians (Table 3).

Table 2. Demographics of caregiver and patient evaluation survey respondents

	Caregivers of children with JIA (n = 113)	Adults with RA (n = 116)	Total (n = 229)
Age, mean (SD) years[a]	41.4 (7.4)	56.1 (13.3)	50.1 (13.4)
Sex, female, n (%)	86 (78)	97 (86)	183 (82)
Education, n (%)			
High school diploma or equivalent or lower education	12 (10)	31 (26)	43 (19)
College or advanced degree	58 (51)	80 (69)	138 (60)
Unknown or NA	43 (38)	5 (4)	48 (21)
Primary language, n (%)			
English	98 (88)	106 (94)	204 (91)
Spanish	5 (5)	3 (3)	8 (4)
Other[b]	8 (7)	4 (4)	12 (5)
Confident to control or manage most health problems (score 7 or more), n (%)	95 (87)	97 (87)	192 (87)
Health literacy: quite a bit or extremely confident in filling out forms by yourself, n (%)	99 (93)	104 (93)	203 (93)

Note: Within each demographic variable, the rows sum to 100% of the population with available data.
Abbreviations: JIA, juvenile idiopathic arthritis; NA, not applicable; RA, rheumatoid arthritis.
[a]Individuals noted as age 26 and younger are removed from demographic data because of potential for misattribution of demographics (commenting on child's age instead of caregiver's age).
[b]Other languages included French (n = 2), Portuguese (n = 2), Amharic (n = 1), Chinese (n = 1), German (n = 1), Hmong (n = 1), Russian (n = 1), Slovak (n = 1), and Vietnamese (n = 1).

Table 3. Use and utility of the PVQ and dashboard among people with arthritis and rheumatologists

	Caregivers of children with JIA (n = 113)	Adults with RA (n = 116)	Total (n = 229)	Pediatric providers (n = 7)	Adult providers (n = 5)	Total (n = 12)
Process measures, n (%)						
Submit a PVQ prior to appt	81 (72)	89 (77)	170 (75)			
PVQ easy or very easy to complete	78 (98)	79 (96)	157 (97)			
Discuss PVQ during appt*	89 (96)	86 (84)	175 (89)			
Concern or goal fully addressed	105 (94)	106 (91)	211 (93)			
Share computer screen or dashboard	100 (89)	105 (91)	205 (90)			
Use of the dashboard, n (%)						
Before the visit				0 (0)	1 (20)	1 (8)
During the visit				6 (86)	5 (100)	11 (92)
After the visit				2 (29)	1 (20)	3 (25)
System usability score, mean (SD)[a]				75.4 (17.6)	79.5 (13.7)	77.1 (15.6)
NPS, n (%)[b]	57	59	59	17	60	37
Detractor (NPS: 0-6)	10 (10)	5 (5)	15 (8)	2 (33)	0 (0)	2 (18)
Passive (NPS: 7-8)	22 (22)	32 (31)	54 (27)	1 (17)	2 (40)	3 (27)
Promoter (NPS: 9-10)	67 (68)	66 (64)	133 (67)	3 (50)	3 (60)	6 (55)
collaboRATE: shared decision-making, n (%)	95 (84)	94 (81)	189 (83)			

Note: Within each demographic variable, the rows sum to 100% of the population with available data.
Abbreviations: appt, appointment; collaboRATE, a 3-item measure of shared decision-making; JIA, juvenile idiopathic arthritis; NPS, Net Promoter Score; PVQ, previsit questionnaire; RA, rheumatoid arthritis.
[a]System usability scores greater than 68 are considered above average.
[b]NPS can range from −100 to 100; scores above 0 are considered good.
*$P < 0.001$.

Female respondents were more likely than male respondents to rate the PVQ as very easy to complete (77% vs. 53%, respectively; $P = 0.01$), and people with high health literacy were more likely than those with limited health literacy to rate the survey as very easy (71% vs. 29%, respectively; $P = 0.03$). Nearly all (96%) caregivers of children with JIA reported discussing PVQ results with their clinicians compared with 84% of adults with RA ($P < 0.01$).

People with lower confidence to manage their or their child's health were significantly less likely than those with high confidence to report submitting a PVQ prior to the appointment ($P < 0.01$), to report that the PVQ was very easy to complete ($P = 0.02$), or to report that the clinician discussed PVQ responses ($P < 0.01$), shared the dashboard or computer screen ($P = 0.03$), or fully addressed their concerns ($P < 0.01$).

No other significant differences in use of the PVQ or dashboard were associated with respondent type, sex, education, or primary language.

Although most clinicians (92%, n = 11) reported using the dashboard with patients during the clinic visit, most reported using it with less than half of their patients with JIA or RA. All clinicians reported using the visual trends in PROs, clinical outcomes, and medications when accessing the dashboard. The mean SUS across pediatric and adult clinicians was 77.1 (SD = 15.6), indicating above-average usability.

The most common changes required by clinicians to incorporate the dashboard into their workflow included developing processes for patients to complete the PVQ (either prior to or during the clinic visit) and identifying when and how to share their computer screen. More than half (55%) of clinicians felt that using the dashboard added some time to the visit.

Utility and impact of the dashboard. Most users indicated that the data and information in the dashboard supported discussions, talking about what matters most, making health care decisions, and creating care plans that could be acted on at home (Figure 2). Caregivers of children with JIA were more likely than adults with RA to report that data and information in the dashboard were useful (93% vs. 83%, respectively; $P = 0.02$). The dashboard helped caregivers of children with JIA, more so than adults with RA, talk with their clinicians about what matters most (89% vs. 75%, respectively; $P < 0.01$).

Half of caregivers of children with JIA or adults with RA and one-third of clinicians indicated that the PVQ and dashboard changed the content or focus of their visit. Most respondents (86%) with a primary language other than English indicated that it changed the content or focus of the clinical visit, compared with 48% of those who spoke English as their primary language ($P < 0.01$).

Respondents who were confident in managing their health were more likely to agree that the dashboard helped them work with their clinicians to make a care plan they could act on at home, compared with those with low confidence (79% vs. 59%, respectively; $P < 0.04$).

Four-fifths (83%) of respondents reported high levels of shared decision-making. Those with high levels of shared decision-making were more likely to be confident in managing their disease than those with low levels of shared decision-making ($P < 0.01$). Perceptions of shared decision-making were not associated with other demographic characteristics.

Two-thirds of caregivers with JIA and adults with RA were promoters of the dashboard and would recommend the
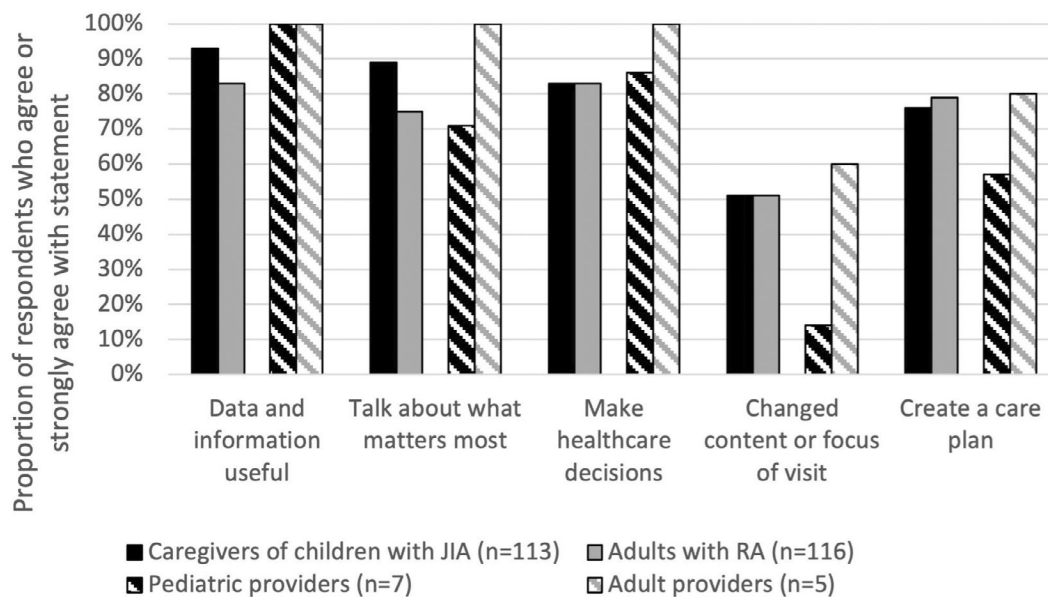
Figure 2. Utility of dashboard. JIA, juvenile idiopathic arthritis; RA, rheumatoid arthritis

dashboard to a peer. Relative to detractors (NPS of 0-6), promoters (NPS of 9-10) were more likely to have higher health literacy (95% vs. 73%, respectively; P = 0.04) and greater confidence in their ability to manage their health condition (95% vs. 60%, respectively; $P < 0.01$). Promoters were more likely to report shared decision-making than detractors (94% [n = 119] vs. 62% [n = 12]; $P < 0.01$). There were no differences between promoters and detractors with respect to other demographic characteristics or perceived value of the dashboard. More than half (55%) of clinicians were promoters of the dashboard. When asked what changes could be made to increase the likelihood of recommending the dashboard, the most common change cited was the need for greater integration with clinic workflows (see Theme 4).

In response to interview questions about the impact of the dashboard, almost all of the 13 caregivers of children with JIA and adults with RA indicated that the dashboard improved quality of care, more than half said it improved decision-making and their ability to achieve better health, and one-third said it resulted in a better relationship with their clinicians. None identified a negative impact of the dashboard.

Prominent themes associated with the utility and impact of the dashboard were identified through thematic analysis of semi-structured interviews and responses to free-text survey entries. Illustrative quotations are shown in Table 4.

Theme 1: Visual displays of information help people make sense of data and understand health information. Caregivers of children with JIA and adults with RA felt that visualization of the homunculus and timeline led to better understanding of health and associated metrics. Visual depictions facilitated an understanding of how medications impacted overall health and

functioning, identified treatments that have or have not worked in the past, and supported shared decision-making regarding next steps in care. The display of data over time helped some people identify changes in their symptoms and functioning that were not otherwise apparent. Reviewing the homunculus allowed patients to have a broader understanding of the potential breadth of joint involvement with JIA or RA.

Theme 2: The PVQ and dashboard support communication. The dashboard offered the opportunity to improve communication and reinforce verbal conversations. It allowed some patients to better articulate how they were feeling. Some patients felt that by completing the PVQ in advance, the visit was more efficient and their clinician was prepared for the visit. Completing the PVQ at home allowed more time to think about concerns and symptoms and decreased the likelihood that their concerns would be forgotten during the visit.

Theme 3: The dashboard supports shared decision-making. The dashboard fostered shared decision-making among people with arthritis and their clinicians. Clinicians often found that sharing the dashboard was of more importance to individuals facing a decision (eg, those who had increased levels of disease activity and were hesitant to switch therapies or those who were on high levels of medicine and were encouraged to de-escalate treatment). Clinicians were less inclined to show the dashboard if patients were doing well and no clinical change was warranted. Clinicians at one institution chose to share the dashboard as a routine part of care with all patients to reduce bias in assuming which patients may most benefit from the dashboard.

Theme 4: Modifications could enhance patient self-management and efficiency of clinical workflows. Several improvement opportunities were identified by caregivers of children with JIA

Table 4. Prominent themes associated with the dashboard

Theme	Illustrative quotation
Theme 1: Visual displays of information help people make sense of data and understand health information.	
CG-JIA and adult with RA	"While she's speaking, I can kind of see what she's saying while she's explaining it. It's like a visual aid with her doing a PowerPoint for me. [...] I feel like it helps [my daughter] look at it, and maybe understand a little bit better, as opposed to just being an overwhelming amount of just knowledge and data. [...] she can see she's going in the right direction as opposed to all those medical terms that kind of tend to especially go over our heads because we're kind of new to this." (caregiver 5)
	"If you show it to me, it's in my mind, I get to look at it and to see it better. Just telling me something it's like, most times people really don't understand. But if you show it to me, it's almost like you're breaking it down. And you allow me to see what's really going on in my body." (adult with RA 5)
Care teams	"I like the longitudinal aspect of it, to show patients overtime, 'This is how you were doing on this therapy, this is how we're doing now and why we changed.' And then I think for patients, it gives them an idea of why we're thinking what we're thinking. So we may explain it to them, but it gives them a visual representation of, 'This is how we're measuring your joint activity. This is what we are looking for as to say you're controlled or not controlled.' And then they can see the graphs over time which I think they like. [...] it just makes it visual for them. It just takes words and makes it into something that they have more meaning about." (adult clinician 1)
	"Patients had no idea that they get a physician global assessment. They don't know that until you explain it to them. And that's where I say, I can use the dashboard to explain these things, and then it'll turn down over time and they'll really be able to see what the difference was before starting medicine to where they are in now. And it just, I think for educational purposes, it's huge." (pediatric clinician 4)
Theme 2: The PVQ and dashboard support communication.	
CG-JIA and adult with RA	"[The homunculus] really helped to open me up because I wasn't being as talkative. And I think that was the turning point. It's like I had something I could show him. [...] so that helped just break the ice. We were looking at that thing instead of putting me on the spot and saying where's the pain." (adult with RA 6)
	"It's obviously a tool to help collaborate and bring people together on the same page and as a possible way of educating each other, like the patient, the families are educating the doctor as to how they're feeling and their symptoms, but at the same time, the doctor can help them by helping them look at maybe some relationships between how they're feeling and their treatment plan." (caregiver 6)
Care teams	"It makes it concrete. I use the JointMan [homunculus] and it just makes it visual for them. It just takes words and makes it into something that they have more meaning about." (adult clinician 1)
	"I think it has the potential to empower, enable families and our team of providers to be more efficient with their communication and be more comprehensive not just with communication but also in their outlook and assessment of arthritis and what that means and how it's doing." (pediatric clinician 2)
Theme 3: The dashboard supports shared decision-making.	
CG-JIA and adult with RA	"I definitely didn't think one of her medicines was working as well until I saw the growth chart, the chart of it moving forward. [...] We kept on it, because the growth was moving, and now it has done a lot of improvement. So it's not something I was excited about until I actually saw it out." (caregiver 5)
	"We can look at it together. And if I'm telling her that a medication is not working and I'd like to try something else, she will bring it up so that I can see the results of every single medication I've tried." (adult with RA 1)
Care teams	"The disease activity over time I think has been the most helpful with the meds and so to say, 'Here's where we were before we added this or when we changed to this, and this is what happened. Here's where you are now.' And then we can use that together to say, 'Where do we want to go next.'" (adult clinician 1)
	"[The dashboard] shows them you're interested enough to look at it, explain things to them and doing shared decision-making with the parent, which everybody really tries to do is to give them time to give their input and stuff, or by showing them the information. It helps a lot." (pediatric clinician 4)
Theme 4: Technology modifications could enhance patient self-management and efficiency of clinical workflows.	
CG-JIA and adult with RA	"Well, I feel at the end of the visit, if we were offered at least a printout of the chart...and kind of see the growth herself and it'll help motivate her to make sure she stays on her medication. Because we're, we're moving places. You know, we're trying to get somewhere with this and we at least have a picture of the chart on our way out and say, Hey, look, I want you to stay on top of your medicine, and doing what you're supposed to be doing so we can stay on track." (caregiver 3)
	"I think it's very busy. If there is a way to make it look more simpler for families, I think that would be nice. And especially if you have a teenager who might be trying to work on understanding his or her health, and so that they can learn how to become advocates for themselves and do this, do take the place of the parent one day. Yeah. To make it more simpler and user-friendly for families would be good." (caregiver 6)
Care teams	"It's not ideal for me because it's not patient facing, they can't see this on their own, we have to show it to them, it's in their chart so they can't access it unless we show it to them." (pediatric clinician 3)
	"The dashboard is not part of the progress note, which is what I'm concentrating on my screen. So then I have to remember to go to a different place, to look at the dashboard. That's one of the reasons I forget looking at it." (adult clinician 2)

Abbreviations: CG-JIA: caregiver of child with juvenile idiopathic arthritis; PVQ, previsit questionnaire; RA, rheumatoid arthritis.

and adults with RA. The most frequently identified improvements were associated with the desire for additional tracking and reporting opportunities (eg, allowing patients the opportunity to annotate notes or add additional data to the dashboard) and improved accessibility outside the clinic (eg, at home via the patient portal). Other opportunities included increasing the size

and font of the dashboard and sharing educational materials to inform patients about the dashboard.

Clinicians reported similar improvement opportunities as those identified by people with arthritis. They also identified challenges in resources required to support PVQ completion during the clinic visit, the need to click into several locations to access the dashboard and complete a documentation note, a lower relative advantage of viewing PROs in the dashboard compared to viewing them in alternative locations within the EHR, and restrictions in the ability to modify the dashboard to better align with existing clinical workflows or documentation practices.

Challenges related to implementation were associated primarily with difficulty aligning the dashboard with existing clinical workflows, additional time to incorporate the dashboard into the clinical visit, and limited availability of tablets for patients to complete the PVQ in the clinic. These challenges were exacerbated by the COVID-19 pandemic and a need to rapidly change numerous other care processes. Although COVID-19 disrupted normal workflows, it offered an opportunity to test use of the dashboard during telehealth visits. The availability of PROs brought additional value when clinicians were unable to do physical examinations during telehealth visits.

DISCUSSION

This study evaluated the experience of completing PVQs and using a dashboard to display and discuss PROs and clinical data during rheumatology visits. We found that electronic PVQ completion is feasible, that these data can be displayed alongside medical data in a visual dashboard within the EHR, and that the dashboard was well received by people with arthritis and clinicians and was seen as informing care. Users felt that the information in the dashboard was useful during discussions and that the dashboard helped them talk about what matters most, make health care decisions, and create a care plan that could be enacted at home. Visual displays of information helped people make sense of data and supported understanding of health information, communication, and shared decision-making. These findings are similar to those reported in prior dashboard studies (8,9).

Use of a PVQ and dashboard may trigger a paradigm shift in health care services for people with arthritis. In this new paradigm, preparation begins prior to the visit with PVQ completion and review. Clinicians share the dashboard and provide increased visibility into the information they use to support clinical assessment and decision-making. The graphical display of information that matters to people with arthritis and their clinicians makes it easier to visualize trends and understand data. This visual display may be particularly useful for visual learners in reinforcing verbal discussions.

Relative to other similar projects (8,9), users were substantially more likely to recommend the dashboard to their peers.

This heightened level of endorsement may relate to the integration into both the patient portal and the EHR. Utility of the dashboard was perceived more favorably by caregivers of children with JIA than by adults with RA and by people who were confident in managing their health. Notably, lower confidence to control and manage health problems was associated with lower likelihood of completing the PVQ prior to arriving at the visit, finding the PVQ easy to complete, and reviewing the dashboard with the clinician. Individuals who were the least likely to recommend the dashboard had lower health literacy and lower confidence in their ability to manage their arthritis. Additional work should explore strategies to improve uptake, ease of use, and benefit of use among people with lower health confidence, people with lower health literacy, and people who speak English as a second language.

We believe this project was significant for several reasons. First, our implementation process was built around an in-depth understanding of local context, quality improvement methodology, and development of strong local lead teams. Second, each of the six sites used the same EHR vendor and had support to build PVQs and adapt the native rheumatology module to meet project specifications. Although there was some variability in implementation across sites, because of factors such as programmer availability, workflow changes, and clinic staff, all demonstrated the feasibility of collecting electronic PROs (a process that was new for some sites) and the ability to adapt the preexisting rheumatology module. Third, the coproduction dashboard is among a very limited number of tools in rheumatology to promote information sharing and shared decision-making based on a combined view of PROs and clinical data (12,13,15,16). To our knowledge, it is the first to do so in pediatric rheumatology and the first to do so in a system that is native to the EHR. Fourth, our mixed-methods evaluation included a geographically diverse sample of people with arthritis and care team members. Interviews provided rich information that supports the findings obtained during postvisit surveys.

Several limitations must be acknowledged. First, because of the novel nature of capturing electronic PROs within the EHR, dashboards at some sites had a limited amount of longitudinal data available to support viewing trends in health over time. Based on experiences of sites with preexisting electronic PROs, we anticipate longitudinal trends in PROs will be enhanced across sites as these data become more robust. Second, data on PVQ completion rates and changes in PROs or clinical outcomes were beyond the scope of this study, limiting our findings on impact. Finally, our evaluation may be influenced by several potential sources of bias, including sampling bias from highly engaged sites and people with arthritis, language bias (dashboard and interviews were only available in English), and educational bias (most respondents had attended some or more college).

Our findings demonstrate that a visual dashboard built within the EHR can support coproduction of rheumatology services for people with arthritis; however, additional modifications are

recommended to further support patient self-management and clinician efficiency. Dashboard enhancements should provide caregivers of children with JIA and adults with RA greater autonomy in accessing and updating dashboards outside the clinical visit. This could occur by providing access to a dashboard summary via the patient portal or by including a snapshot of the dashboard within the patient's postvisit summary. Moreover, workflows should be refined to encourage clinicians to use the dashboard during both in-person and telehealth visits. There also are opportunities to enhance the collection of patient-generated data to routinely elicit what matters most to people with arthritis, promoting better communication and relationships between patients and clinicians (28). This approach can lead to greater understanding of patient preferences, concerns, and goals and thereby advance person-centered care. Future work must explore ways to better support people with low health confidence and low health literacy to coproduce health care services.

Looking to the future, PVQs and dashboards have the potential to standardize the collection of PROs and to support health care service delivery, quality improvement, and research. There is an opportunity to spread and scale this work by partnering with pediatric and adult registry organizations, such as the Childhood Arthritis and Rheumatology Research Alliance (CARRA) (29), the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) (30), and the American College of Rheumatology's (ACR) Rheumatology Informatics System for Effectiveness (RISE) registry (31). Broader spread and uptake can have substantial benefit at multiple levels, particularly with burgeoning population health and data-sharing capabilities supported through EHRs, and could enable further studies of the impact of the PVQ and dashboard on disease activity and other health outcomes across multiple sites. Of greatest importance, the dashboard has the potential to offer real-time capture, sharing, discussion, and shared decision-making if used optimally and consistently, supporting greater engagement in self-care and coproduction of health care services and ultimately better health and outcomes for people with arthritis.

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All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Ms. Van Citters had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.
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