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The authors wish to acknowledge the leadership and financial support of the Arthritis Foundation for this work.

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SUMMARY

This project illustrates how patients and families can work together with their physicians and care teams to develop a dashboard tool that displays patient-reported data, clinical data, and medications over time that can be used during a clinic visit to support partnering and shared decision making. This group co-designed and built a paper prototype dashboard that was tested on patients and families. We report the experience from the prototype on 36 patients and their families.

OBJECTIVES

- The **overarching goal** of this Arthritis Foundation (AF) initiative is to build a Rheumatology Learning Health System, which is a framework for leveraging data generated at the point of care for improvement and research in order to support better health and high-value care for people living with a rheumatic condition.
- The **initial proof-of-concept project** is focused on co-designing, developing, and testing a pediatric dashboard to support the partnership for coproduction at the core of the model.
- The **aim of the dashboard** is to support meaningful conversations and shared decisions about care and treatment plans among patients and families and their physicians and care teams. We will do this by incorporating patient-reported outcomes and #1 concern alongside clinical and treatment (medication) data.



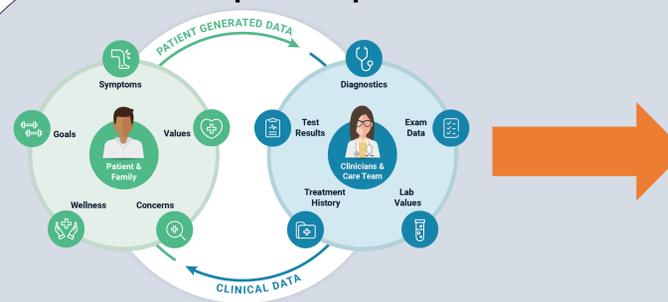
METHODS

- Engaged in a **human-centered design process** facilitated by bi-weekly webinars
- Involved **multi-disciplinary clinical care teams and parent partners** from 3 pediatric rheumatology sites (Hackensack, Stanford, and Wake Forest)
- Created a **Parent Partner Group** to bring the voice and experiences of parents and families into the process
- Participated in a **nominal group technique** to identify and cull data elements to populate an initial prototype of the dashboard



Parent Partner Group

Partnership for Coproduction



1. DEFINE

- The opportunity exists to achieve better outcomes and value of care based on what matters most to patients.
- Currently, real-time data does not readily exist at the point of care in a way that supports coproduction of care based on patient preferences and values.
- This initiative is focused on developing a data display tool that feeds forward patient-reported and key clinical data along with medications that can be used during a clinic visit to foster partnership and shared decision making.

2. UNDERSTAND

18 Team Members

Hackensack Team	Stanford Team
Yukiko Kimura, Physician Champion	Tzielan Lee, Physician Champion
Doreen Tabussi, Nurse Practitioner	Quoc Du, Nurse Practitioner
Ivy Hernandez-Jones, Nurse	Melissa Roybal, Nurse
Johnslyn Rochester, Front Desk Staff	Maria Martinez, Patient Care Coordinator
Vincent Delgaizo, Parent	Marielena Vallejo, Medical Assistant
Cathy Kuncken, Parent	Jennifer Danielson, Parent
Daniela Vitelli, Parent	

Wake Forest Team

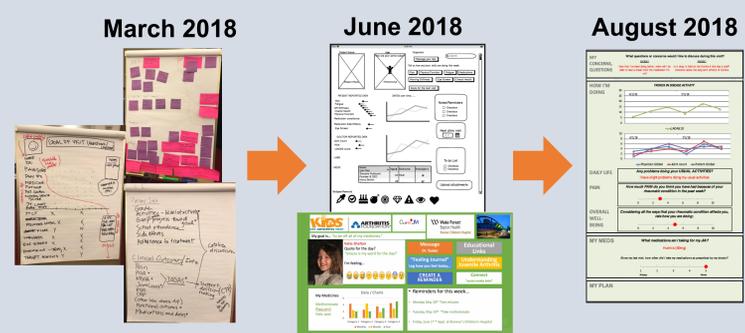
Alysha Taxter, Physician Champion
 Brittany Donaldson, Physician Assistant
 Lauren Vannoy, Research Coordinator
 Robert and Sonya Shelton, Parents

Flowcharts and End User Personas

Co-Design and Implementation Process



Dashboard Design Consensus



Dashboard Data Elements

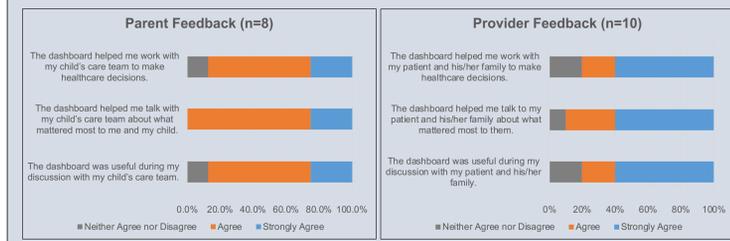
Domain	Description
1. Concerns, Questions	Patients and parents' questions or concerns for discussion in the visit.
2. Patient Global Assessment	Indicates patient's overall well-being.
3. Medication Adherence	Indicates how often medications are being taken as prescribed.
4. Physical Function/ Mobility	Overall mobility and overall upper extremity function scores (Patient-Reported Outcomes Measurement Information System).
5. Medication Side Effects	Symptoms from medications being taken (Juvenile Arthritis Multidimensional Assessment Report).
6. Pain Interference	Overall pain interference score (Patient-Reported Outcomes Measurement Information System).
7. Joint Count	Number of tender and/or swollen joints.
8. Physician Global Assessment	Physician's assessment of patient's overall well-being/disease activity.
9. Disease Activity	Juvenile Arthritis Disease Activity Score (JADAS).
10. Liver Toxicity	Alanine Aminotransferase (ALT)—liver toxicity test.
11. Current and Previous Medications	Medication name, formulation, dosage units and amounts.

4. TEST

Coming Soon – Electronic Dashboard

RESULTS

Paper-based testing of the dashboard was conducted with 36 Juvenile Idiopathic Arthritis patients (67% female and 33% male, ranging in age from 3 to 20 years); 87% of parents and 80% of providers responded positively about its usefulness during discussions.



Important themes were uncovered about the value of the dashboard to both parents and providers.

Pre-Visit Planning – Sharing of Concerns, Questions, Well-Being	Sharing Data – Visualization of Data and Health Information	Partnering – Co-Assessing and Co-Deciding Next Steps
<p>Parent</p> <p>We were able to write out our questions prior so that we didn't forget anything during the appointment.</p>	<p>Parent</p> <p>Showed what was improving and what wasn't.</p>	<p>Parent</p> <p>Able to make decisions based on results seen in the dashboard.</p>
<p>Provider</p> <p>We often forget to ask certain questions, and the dashboard reminds us to focus on the patient's concerns rather than just looking at a clinical picture.</p>	<p>Provider</p> <p>The graphs were helpful to show that she was doing well, could support us stopping medications.</p>	<p>Provider</p> <p>Opened up conversations about implementing new plans and starting new medications.</p>

CONCLUSIONS

- Using a human-centered design process with 3 pediatric rheumatology pilot site teams yielded a blueprint for a dashboard tool.
- Promising early results for its use at point of care to foster meaningful conversations and shared decision making about care and treatment plans between patients and families and their physicians and care teams were experienced.

FUTURE DIRECTIONS

- Create an electronic dashboard for a planned launch in the three pilot sites beginning in November 2019.
- Evaluate measures of the impact on patient satisfaction, clinic work flow and provider joy in work, and patient PRO and clinical outcome data over time.
- Spread and scale the dashboard to other pediatric rheumatology sites upon completion of the pilot phase.