Implementation of the ICHOM Congenital Heart Disease Standard Set: Lessons From Our Patients

Ariane Michelson, MPH[1], Sidra Ahmad[1], Kevin Hummel, MD[2], Jessily Ramirez, EPHM, IMPH[3], Sarah de Ferranti, MD, MPH[1], Kathy Jenkins, MD, MPH[1], Susan F. Saleeb, MD[1]

[1] Department of Cardiology, Boston Children's Hospital, Department of Pediatrics, Harvard Medical School, [2] Department of Pediatrics, Divisions of Pediatric Critical Care and Pediatric Cardiology, University of Utah [3] Center for Applied Pediatric Quality Analytics, Boston Children's Hospital
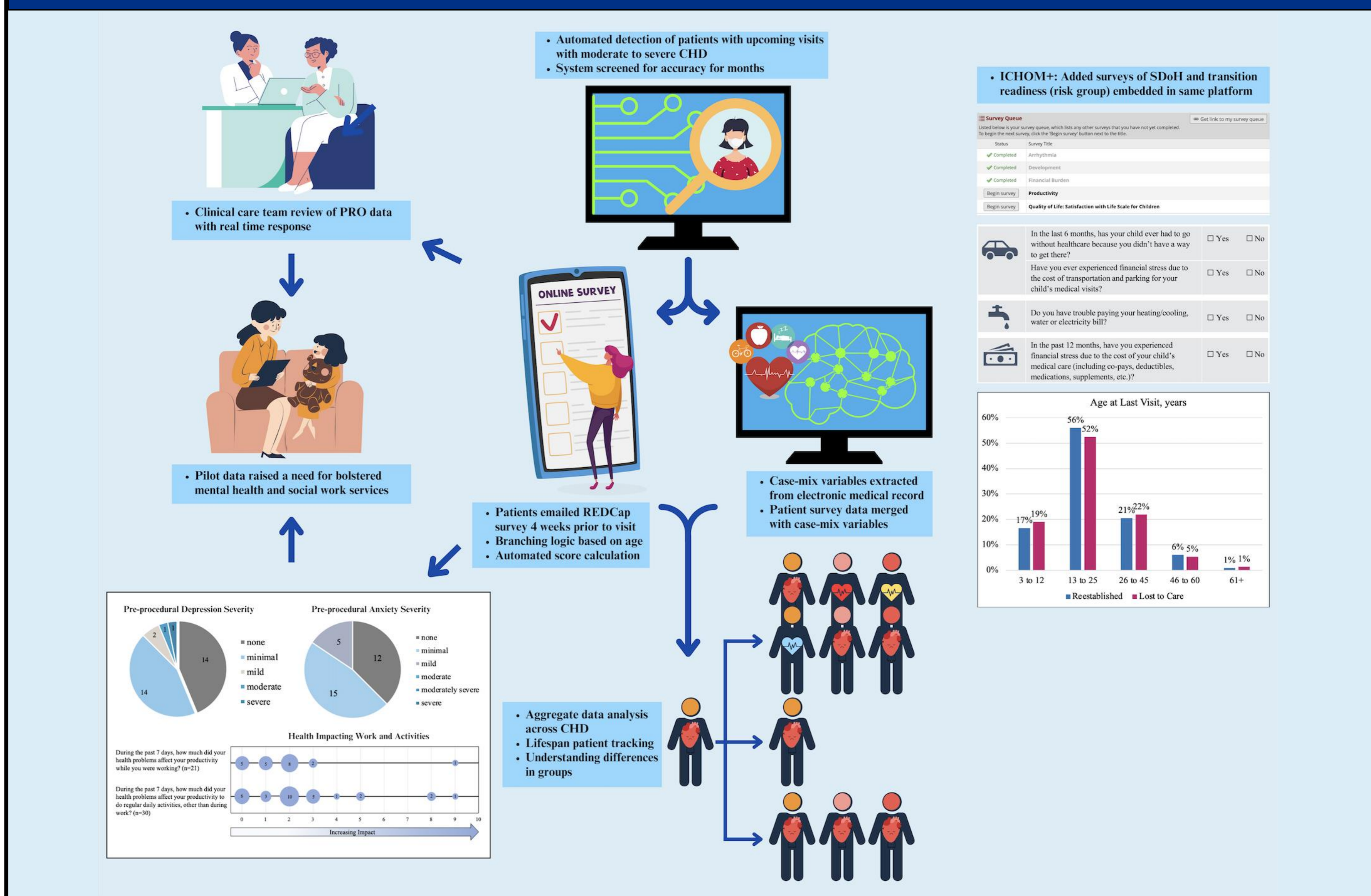
INTRODUCTION

- Congenital heart disease (CHD) is the most prevalent birth defect, with high cost and healthcare utilization across a lifespan.
- Implementation of the ICHOM CHD standard set within our quaternary-care, academic, pediatric Heart Center, with >30,000 visits per year and >7500 unique patients requiring annual cardiology care requires robust IT systems, allowing personnel to focus on patient reported outcomes (PRO) review and patient care needs.
- Implementation strategy was informed by a pilot in 30+ patients undergoing pulmonary valve replacement (PVR).

METHODS

- Weekly review of pending patients with moderate to severe CHD used to refine automated screening process for eligibility.
- REDCap survey development continues to evolve with branching logic by patient age and response to reduce survey fatigue and improve response accuracy.
- Data extraction for the case mix index variables continues to iterate for ideal data display and interpretation.
- Training ongoing with nursing, mental health, and social work teams for rollout.

IMPLEMENTATION STRATEGY

- Automated detection of patients with upcoming visits with moderate to severe CHD
- System screened for accuracy for months
- Clinical care team review of PRO data with real time response
- Pilot data raised a need for bolstered mental health and social work services
- Patients emailed REDCap survey 4 weeks prior to visit
- Branching logic based on age
- Automated score calculation
- Case-mix variables extracted from electronic medical record
- Patient survey data merged with case-mix variables
- Aggregate data analysis across CHD
- Lifespan patient tracking
- Understanding differences in groups
- ICHOM+: Added surveys of SDoH and transition readiness (risk group) embedded in same platform

RESULTS

- Using Proctor implementation outcomes from the PVR pilot, we outlined barriers to feasibility (time burden of personnel), adoption (process for identifying patients), penetration (multimodal capture of patients), and sustainability (need for automation) to form our implementation framework.
- High impact results from the pilot have facilitated learning and improvement in the system, for which mental health and social work support will be bolstered for PRO roll out.
- Collaboration with IT ongoing for data integration and display for individual patient and aggregate population.

CONCLUSIONS

- Full ICHOM implementation in children and adults with moderate to severe CHD has been informed by PVR pilot.
- Pilot identified resources for optimal, patient-centered care.
- Building IT, nursing, social work, and mental health support systems will be key to overcoming barriers to implementation and optimizing patient needs.

Susan F. Saleeb, MD, Department of Cardiology, Boston Children's Hospital, Department of Pediatrics, Harvard Medical School