



**DSRIP Innovation Grant Poster Session
May 22, 2019**

Starting March 1, 2018, Boston Children's Hospital, and its affiliated specialists and primary care physicians in the Physicians' Organization at Children's Hospital (PO), and community-based primary care physicians in the Pediatric Physicians' Organization at Children's (PPOC) began participating in a new Medicaid Accountable Care Organization (ACO) Program in partnership with Tufts Health Public Plans (THPP).

Massachusetts Medicaid (MassHealth) is providing ACOs with one-time infrastructure funding through the Delivery System Reform Incentive Payment (DSRIP) program to support certain resource needs and innovation. The ACO used a portion of these funds to award eleven grants across the institution for proposals aimed at furthering the transformation of the pediatric delivery system.

Projects funded through the DSRIP Innovation Fund were required to be aligned with at least one of the following:

- ACO clinical priorities
 - o Complex Care
 - o Behavioral Health
 - o Social Determinants of Health
- Activities that will have an impact on the clinical, social, or financial success of the Medicaid ACO
- Lead to operational improvements across the BCH enterprise for the care of MassHealth patients

On May 22, 2019 each funded project produced a poster for a poster session held at the Inn at Longwood Medical. This packet contains electronic copies of their posters.

Please contact DSRIP.Innovation@childrens.harvard.edu with any questions.



DSRIP Innovation Project Titles and Project Leads

Improving care integration for children with complex gastrointestinal conditions.....1
Dr. Maireade McSweeney

Reducing 72 Hour Return Emergency Department Visits.....2
Dr. Joel Hudgins

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Dr. Kathleen Conroy and Dr. Eli Sprecher

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Dr. Laura Amar-Dolan

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Bringing the ICU Home: A Community-based Care Model for Children with Chronic Respiratory
Failure.....11
Dr. Robert Graham

DSRIP Innovation Grant Project Alignment with Boston Children's ACO Priorities

Project Title	Clinical Priority Areas			Operational Improvement
	Behavioral Health	Complex Care	Health Related Social Needs	
Improving care integration for children with complex gastrointestinal conditions		x		x
Reducing 72 Hour Return Emergency Department Visits				x
Integrated Care Management in Neurology		x	x	x
Health Coaching for Parents of Children with Medical Complexity		x	x	
Simulation Training for Caregivers of Tracheostomy Dependent Children		x		
Social Risk Identification, Response, and Innovation	x	x	x	x
Shared Care: Innovative Models for Decreasing In-Person Specialty Consultations		x		x
Complex Urological Care: Achieving the Triple Aim Through Care Integration and Telemedicine		x		x
Enhancing Care Integration to Decrease Health Care Utilization in Children with Medical Complexity		x		x
From Evidence to Impact: Demonstrating the Cost Effectiveness of a Scalable Cognitive-Behavioral Therapy Intervention for Pediatric Pain	x	x		
Bringing the ICU Home: A Community-based Care Model for Children with Chronic Respiratory Failure		x	x	

Improving Care Integration for Children with Complex Gastrointestinal Conditions

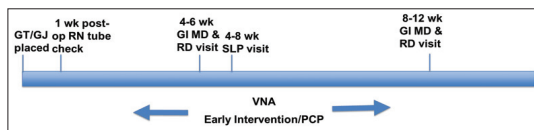


Perkins J, Hartigan L, Lawlor L, Capuccio L, Yu M, Bizak M, Vukson K, Paone C, Itchapurapu S, Fournier G, Docktor M, Lenz C*, Antonelli R†, McSweeney M

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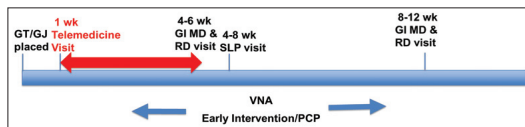
Background

- Approximately 250-300 BCH patients a year will undergo permanent gastrostomy (GT) or gastrojejunostomy (GJ) tube placement
 - 10-12% patients will experience a major complication within 6 months of their tube placement*
 - 13% patients will require ED visit for a tube related issue within their first 6 wks of placement; consistent with national data reporting ~10% patients having a GT related ED visit within 30 days of placement
- Many patients are medically complex with multiple specialists, care teams/providers involved in their care
 - Almost 1/2 of all patients are evaluated for GT placement while inpatient
- Standard Post-operative "Tube Care" recommended**



SMART Aim

- To implement a 1 wk follow-up telemedicine RN/NP visit in order to decrease the use of Emergency Room visits by 10% in the first month of children being discharged home after new tube placement

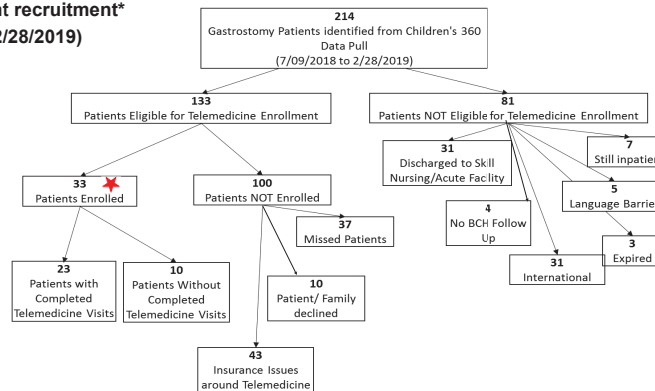


Secondary Aims

- Monitor frequency of: (1) hospital readmissions, (2) GI phone calls, (3) GI clinic visits, all within 30 days of discharge
- To develop and utilize a "Tube Action Grid" to unify and track completion of recommended post-operative care tube recommendations
 - Provided to patients/families at discharge and reviewed during telemedicine visit
 - Developed electronic "App" Action Grid (Dock health Initiative)
- To assess clinician satisfaction with telemedicine visit, record care coordination needs met using a Care Coordination Measurement Tool (CCMT)
- Included patients: (1) were s/p GT placement during project time period and (2) did not have a history of having a GT surgery within a year

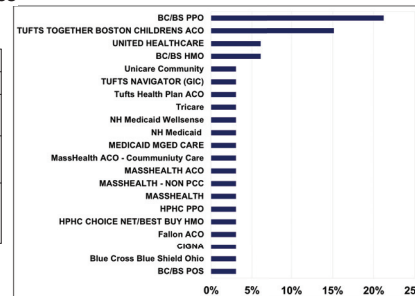
Evaluation

- Patient recruitment*** (7/9/18-2/28/2019)



- Telemedicine patient demographics** (n=33)

Median (IQR) age	15 (4, 60.5) months
Male	15 (45.5%)
Language	32 (97%)
• English	
• Spanish	1 (3%)
Median (IQR) time between Tube placement & D/C	3 (2, 4.75) days



- 17 (52%) patients discharged from inpatient GI Service
- 24 (72%) completed an action grid. "App" action grid created but no electronic action grids were successfully completed by QI team

- Hospital resource utilization:**

	Current Practice (n=100)	Telemedicine Patients (n=33)
ED Visits	8/100 (8%)	1/33 (3%)
Rehospitalizations	6/100 (6%)	1/33 (3%)
GI Clinic visits	48 (48%) patients 81 visits (1.6 visits/pt)	20 (61%) patients 31 visits (1.5 visits/pt)
GI phone calls*	31 (31%) patients 54 calls (1.7 calls/pt)	8 (24%) patients 15 calls (1.8 calls/pt)

*Documented in EMR

Evaluation (continued)

- Top 3 reported outcomes from CCMT (n=14)**

Care Coordination Needs Met	1. Clinical issue related to GI condition 2. Growth/Nutrition 3. Order for prescriptions/supplies/services
Outcomes Occurred	1. Advised family on home management 2. Anticipatory guidance/parental support 3. Reviewed lab results
Outcomes Prevented	1. Specialist/ Clinic Visit 2. Gap in Medication/Supply problem – Changing Prescriptions 3. Urgent Clinic Visit

- Qualitative Clinician Reported Experience with Telemedicine:**

Positive:

- Good experience overall
- Helpful to not have patient return to the clinic

Negative:

- Visualization problems: Challenges assessing skin and stoma site noted
- Connection issues: Difficulties with connection or one provider still had to make a f/u phone call to hear the families

Budget

	Estimated costs	Funding used*
Total	\$155,648.5	\$107,865
Staff Salary/Fringe (Included: Project Manager, QI Manager, Project Coordinator, Nursing Director, Outpatient NP)	\$106,548	\$82,828
Subcontract to Innovation program/telemedicine costs	\$31,126.5	\$25,037

*As of 3/2019

Challenges and Lessons Learned

- Required a full time project coordinator position for recruitment and insurance review
- Enrollment challenges (patients discharged over weekends, frequent f/u appointments)
- Action Grid and "App" was not in inpatient and outpatient electronic workflow
- Insurance coverage issues
 - Median time required to assess coverage: 25 (16.3, 43.8) min and median 2 (1, 2) calls/patient
 - Insurance barriers to covering telemedicine; only 2 Tufts BCH ACO pts completed telemedicine visits

Future Directions

- Assess patient experience with telemedicine
- Explore usage of telemedicine for other visit types (i.e. Urgent tube care visits, after discharge from skilled care facility)

Joel D. Hudgins, M.D., Anne Stack, M.D., Cathy Perron, M.D., Annie Seneski, B.S., Pamela Schubert, R.N., and Kathleen Conroy, M.D.
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Background

- Return emergency department (ED) visits are challenging to providers, patients, and the healthcare system in general
- In particular, preventable ED visits represent an opportunity for significant improvement in care and cost reductions

Project Goals

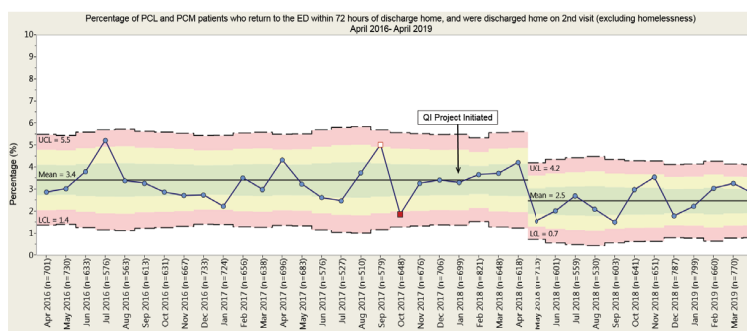
- To reduce percentage of PCL/PCM patients who return to the ED within 72 hours of initial discharge, and are discharged home again, by 20% (from 3.4 to 2.7%)
- To understand reasons that families and patients return to the ED for care within 72 hours of discharge

Activities Completed

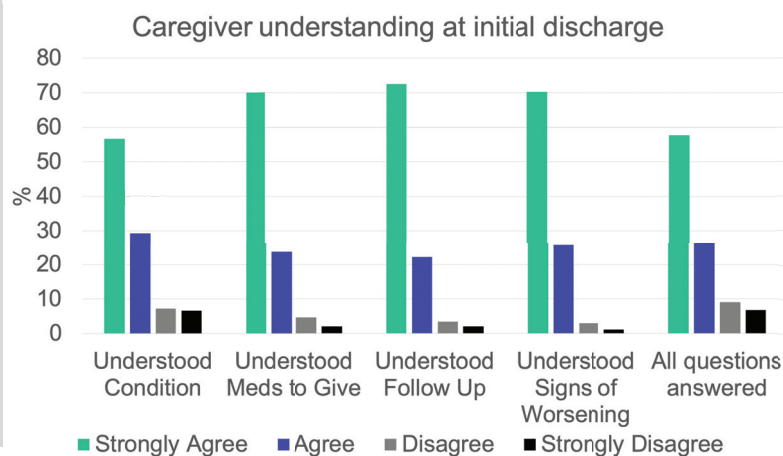
- Quality improvement (QI) interventions involving ED and Primary Care Longwood (PCL) and Primary Care Martha Eliot (PCM) staff
- Interventions included:
 - Development of a key driver diagram
 - Improved communication between ED and PCL/PCM staff
 - Educational handouts designed for families with primary care at PCL/PCM
 - Educational handouts aimed at differentiating need for urgent vs emergent care
- Completed over 300 surveys by families of patients returning to ED for care within 72 hours, highlighting areas for future intervention

Evaluation

Return Visit Rates for PCL/PCM Patients



Returning Families Survey Results



Dollar Amount Invested in Project

Amount Invested	Amount Spent
\$107,191.77	\$107,191.77

Challenges and Lessons Learned

- Impacting change in outcomes requires intervening much earlier than at the time of the outcome
- Families return to the ED for many reasons, but being sent by pediatricians is a major one
- Education is helpful but not a replacement for major structural changes
- Working across specialties is challenging but incredibly rewarding, and offers the most promising way to affect change in the future

Next Steps and Sustainability

- Improve the ED discharge process through targeted, condition specific interventions
- Involving the entire Pediatric Physicians Organization at Children's (PPOC) in improving communication and working to reduce revisits
- Overhaul of the primary care referral process
- Role for symptom checker software (such as Buoy™) to empower families to make decisions regarding when to return



Background & Project Goals

The Department of Neurology has a large population of highly complex patients placing them at high risk of requiring high cost acute care as well as chronic services. Our project is designed to optimize elements required for optimal integrated care management, family education, and clinical touch points to improve care and avoid use of urgent care facilities when expert management can prevent such costly complications.

Our Team

Scott Pomeroy, MD, PhD, Phillip Pearl, MD, Deborah Shiers, MSN, RN, CNRN, Colleen Gagnon, BSN, RN, CNRN, Jennifer McCrave, RN, BSN, CNRN, Ellie Reece, MPH, Nathan Keegan, MS, Richard Antonelli, MD, MS, Annalee Antonetty, CPHQ

Administrative	Nursing	Physicians
• Elizabeth Beers	• Carole Atkinson	• Elizabeth Barkoudah
• Jeslyn Monaghan	• Patricia Gannon	• Ann Bergin
• Katie Stylien	• Paige Marshall	• Jeff Bolton
• All Neurology Admins	• Candice Marti	• David Coulter
• Quality Improvement	• Kate Mysak	• Claudio DeGusmao
• Madeline Chiujea	• All Neuroscience RNs, NPs	• Tobias Lodenkemper
• Alex Fialkow		• Arnold Sanservere
Integrated Care	Social Work	• Siddharth Srivastava
• Casey Fee	• Chris Ryan	• Coral Stredny
• Hannah Rosenberg		• All Epilepsy Attending Physicians

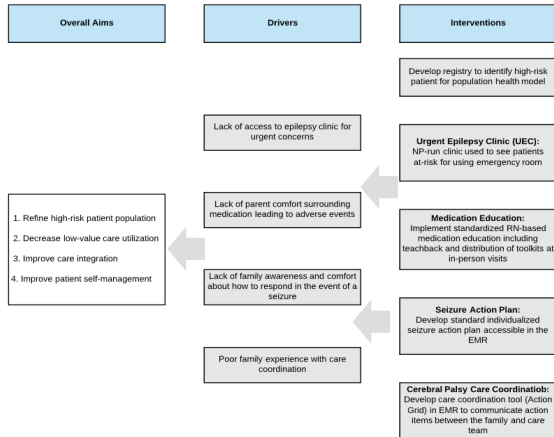
Budget

Awarded: \$278,837 **Spent:** \$278,837
Allocated to Staffing

Nursing	Administrative	QI Team
\$187,652	\$62,246	\$28,939

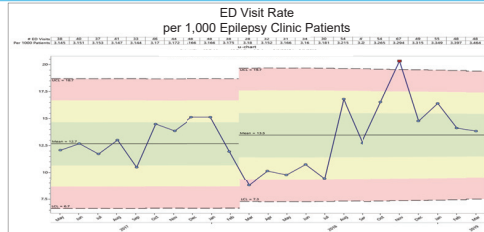
Interventions

Integrated Care Management in Neurology



How things went...

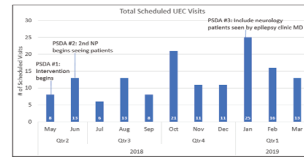
Primary UEC and Medication Education Outcome Measure



Urgent Epilepsy Clinic

Who is eligible to use UEC?

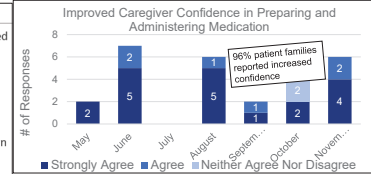
- Changes in seizure activity: Acute clinical changes and/or change in location of patient indicated, increased seizures or change in seizure frequency or pattern of seizure activity
- Medication Changes: Patients with multiple medication changes (i.e. seizure, transition, new dose change)
- IEE Referrals
- Urgent Services (Epilepsy or ICH): "Unplanned admission pathway"
- Medication Adherence Issues: Adverse medication/IEE side effects (e.g. sedation, cognitive effects, behavioral changes, risk, fatigue, etc.)
- Discharge or medication administration errors (e.g. wrong medication, wrong dose, wrong frequency, wrong route)



- RNs reported an ED visit was avoided 70% of the time using Care Coordination Measurement Tool (CCMT)
- Potential Cost Savings:
 - \$275 Savings per UEC visit vs. ED visit
 - \$31,900 total savings (\$275 x 116 encounters)
 - 27% reduction in the charges that would have been submitted through the ED for these 116 encounters

Medication Education

- Referral Criteria**
- Non-English speaking; interpreter needed
 - History of medication non-adherence
 - Liquid medications
 - Clobazam/Onfi prescription
 - New medication prescribed
 - Titration: any change in dose, up or down
 - New rescue plan



- 30 education sessions completed
- 0 patients went to the ED within 30-days of their education session

Seizure Action Plan

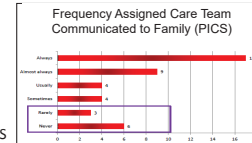
- Developed a standard individualized SAP
- Paper version fully implemented with Cerebral Palsy Neurology patients
- Rolled out on paper to inpatient & outpatient Neurology & Epilepsy services
- Updated SAP based on pilot feedback

Standard Individualized SAP

Section	Content
Header	...
Diagnosis	...
Medications	...
Seizure Action Plan	...
Emergency Instructions	...
Footer	...

Cerebral Palsy Care Coordination

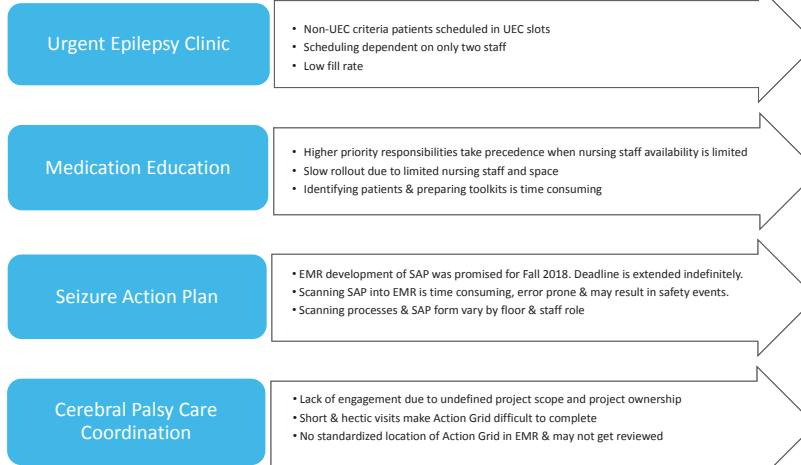
- 43 CP families completed Pediatric Integrated Care Survey (PICS)
- Planned pilot for care coordination tool (action grid) on paper to address needs identified in the PICS



Action Grid

Dr. Office	Intervention	Responsible Party	Start Date	End Date	Status
...

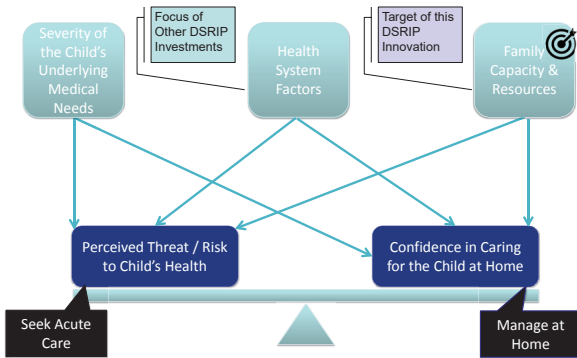
Challenges



Next Steps

- Reinforce UEC criteria
- Consider broadening UEC criteria
- Train all administrative staff to schedule UEC slots
- Optimize number of UEC slots
- Redistribute & reprioritize responsibilities to ensure a nurse is available as needed
- Include 2 additional providers to continue assessing feasibility
- Trial use of billable RN follow-up visits
- Explore use telehealth visits
- Continue to advocate for EMR development
- Educate staff on standardized SAP & scanning process
- Distribute scanning responsibilities
- Clear articulation of leadership for the intervention
- Further refine project scope based off PICS data
- Optimize coordinated visit workflow
- Standardize Action Grid scanning process
- Continue to advocate for EMR development

BACKGROUND/OBJECTIVES



Aims:

1. Understand parental activation and self-efficacy, child quality of life, and experience of care in our Rainbow / KASA population (medical home program for children with medical complexity in Boston Children's Primary Care Practices)
2. Study the impact of health coaching on activation, efficacy, quality of life and experience of care among the Rainbow/KASA population

METHODS/DESIGN

Health Coaching is a way of providing patients with the knowledge, skills, and confidence to become informed and active participants in their care

Uses motivational interviewing and goal setting to identify steps patients can take to change behaviors leading to greater health

Has been shown to improve outcomes in adult patients with chronic conditions managed in primary care

Some adult primary care systems use health coaches at the center of care

- 63 patients randomized to control (n=41) and health coaching intervention (n=22)
- This study was awarded \$147,369 of Delivery System Reform Incentive Payment (DSRIP) funding over 19 months
- Total invested in the project: \$147,369

BASELINE DATA

Our Baseline Data Showed High Levels of Activation, Lower Health Related Quality of Life (HRQoL) and Patient Experience Scores

- 88% of parents were in the highest activation tiers
- Parents had high baseline perceived self-efficacy in communication with providers (23.25 points out of 25 point maximum)
- Mean HRQoL was one standard deviation below general population (40.2, range 25.5 to 64.4)
- 78% top box for overall rating of patient experience

Our Baseline Results Had Some Interesting Associations

- Latino parents had higher activation than other racial/ethnic groups
- Our HRQoL scores were not associated with race/ethnicity or education
- Parents who had more positive experience with their child's healthcare were more likely to be activated but not necessarily to have a higher HRQoL
- Utilization was not associated with activation or HRQoL

THE COACH'S ROLE



A Patient's Story

- 19-year-old girl with obesity, hypertension, and low vitamin D
- Created an action plan with the coach
 - Actions included behavior change, dietician follow-up
- Weight decreased by 2kg, BP improved from 136/72 to 108/64
- Adolescent's confidence in ability to maintain change increased

INITIAL PILOT RESULTS

- Parental activation did not change much
- The intervention group activation score increased by 3.8 points (out of 100) while the control group declined by 0.7 points (p = 0.4)
- Parental self-efficacy scores increased by negligible amounts
- HRQoL scores increased by 0.1 (intervention) and 0.02 (control) standard deviations (p = 0.7)
- No show rates decreased by a negligible amount (<2%) in both groups

LESSONS LEARNED

- Providers see significant potential for coaching in this population
- Describing new models of care to parents has been difficult
- Integrating coaching into existing clinic flow and existing complex care teams is a challenge
- Many of our parents are very activated
 - Perhaps identifying patients after a time of significant stress / change in status would work better
- Our parents feel self-efficacious but perceptions of their child's quality of life is very dynamic
- We have room to improve our patient experience

NEXT STEPS

- Launch health coaching 20 this spring with a focus on children with medical complexity who:
 - Providers/complex care teams identify as potentially benefiting from a coach
 - Have a new complex chronic condition
 - Were hospitalized or had frequent ER visits in the last 6 months
- Continue to monitor post-coaching utilization in the initial cohort

Slides with PAS Presentation on Baseline Data



Slides with More Details on Coaching Model



Email the Authors to Continue this Conversation!



Simulation Training for Caregivers of Tracheostomy Dependent Children

BACKGROUND

A growing population of medically complex children are cared for at home with tracheostomy. Families provide chronic intensive care with varying amounts of home nursing and technology support. The discrepancy in expertise of personnel in acute care setting and home caregivers may contribute to family stress, increased health care utilization and catastrophic complications.

AIMS

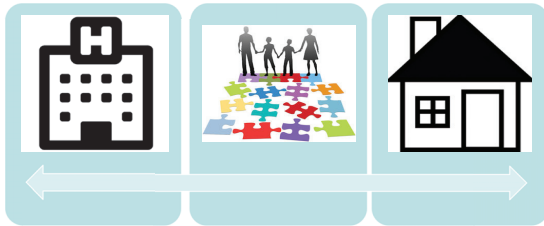
Explore the experience of families transitioning home with a new tracheostomy to inform discharge education and process.

Develop a high fidelity simulation curriculum for home caregivers of children with tracheostomy and long term mechanical ventilation (LTMV) dependence.

Evaluate the impact of simulation curriculum on knowledge, self-efficacy and health care utilization.

NEEDS ASSESSMENT

Semi-structured interviews with twelve patient families. Qualitative analysis of interview transcripts.

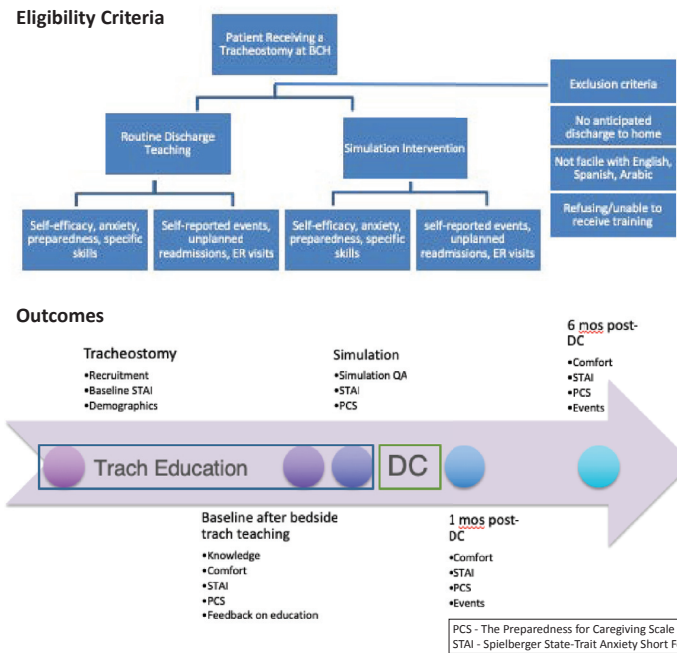


Key Findings:

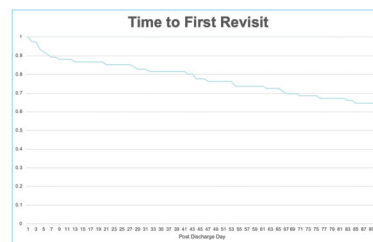
- Comfort with routine care
- Desire for more training managing emergencies
- Concerns about home care nurse availability and preparedness
- Durable medical equipment coordination
- Expectation setting and communication challenges
- Formal and informal systems of support

Specific experiences used to develop simulation curriculum.

METHODS

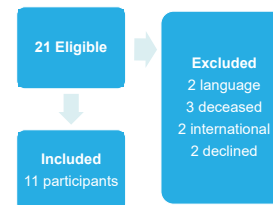


Change in the knowledge, confidence and skills of home caregivers.
Self-reported clinical events, emergency visits and readmissions.



Baseline Revisit Rates 2017 (N=75)

7 days 9.3%
30 days 17.2%



SIMULATION CURRICULUM

Educational needs of families and home care nurses

Simulation Scenarios:

- Simulation Orientation
- Room and Equipment Setup
- Occlusion
- Displacement
- Bleeding
- Circuit leak
- Water aspiration from vent

Curriculum aspects individualized for each patient and family.



CAPE and Trach SME Educators completed simulation training
Pilot sessions with novice providers completed
Pilot sessions with expert families ongoing
Baggage and suctionable attachment for simulation mannikin developed

CHALLENGES

- Engagement of stakeholders.
- Coordination of schedules with busy families, educators, simulation center.
- Future budget for RN and RT educator time.

NEXT STEPS

Incorporate simulation into the discharge teaching process for families with new tracheostomy and home care nurses.

Continue evaluation of baseline and post-intervention knowledge, self-efficacy and health care utilization.

BUDGET	
Research Assistant	1,310
Program Coordinator	1,771
Trach Trainer	7,500
Qualitative Data Support	2,129
Translation Services	731
Simulation Delivery – RT Educator Time	11,615
Gift cards for participant	250
Parking	1,000
Total	26,307

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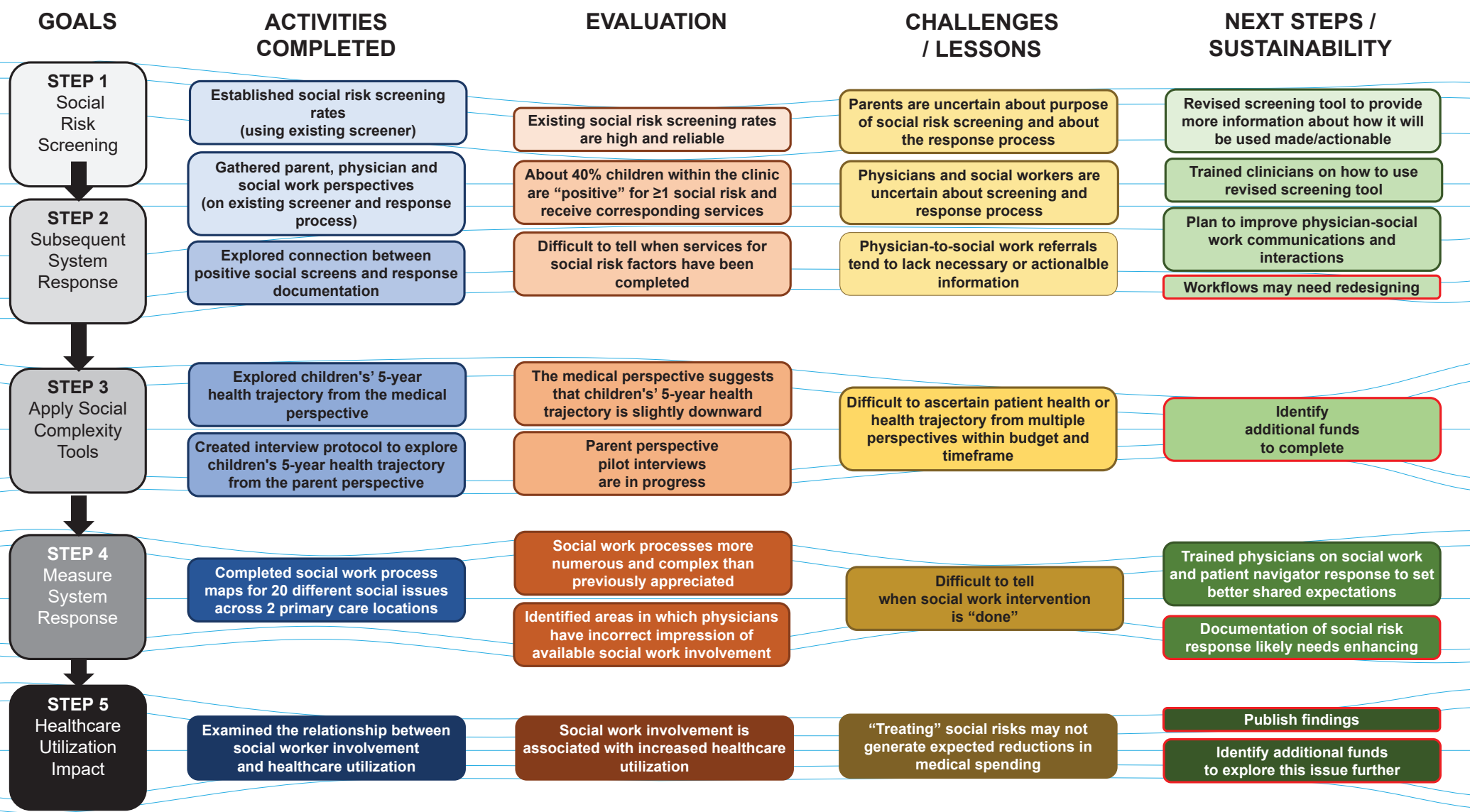
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BACKGROUND

- The quality of children's health is compromised by poor care coordination between primary care providers (PCPs) and specialists
- Common challenges with referral systems include inadequate processes to communicate referral questions, request expedited appointments, and receive advice

PROJECT GOALS

- Enable PCPs to communicate their referral questions to specialists and save them to the Electronic Medical Record (EMR)
- Permit PCPs to request advice and expedited appointments
- Facilitate scheduling by sending routine referral requests directly to specialty departments
- Enable PCPs to track referrals so they can contact families for unscheduled or missed appointments

ACTIVITIES COMPLETED

- Starting April 2018, the Primary Care at Longwood clinic (PCL) at Boston Children's Hospital implemented an electronic consultation and referral system (Shared Care) for select departments:
 - Dermatology (Derm)
 - Gastroenterology (GI)
 - Neurology (Neuro)
- Tracked uptake monthly and monitored specialist responses and appointment wait times
- Administered survey prior to implementation to measure PCP experience with referral process
- Interviewed caregivers and conducted provider focus groups to assess experiences with the referral system

Figure 1: Shared Care Form in EMR

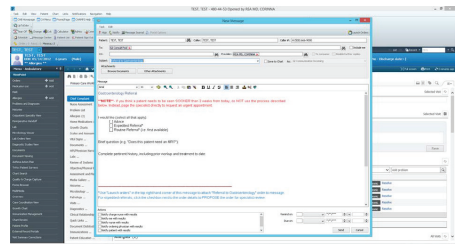


Figure 2: Shared Care Process

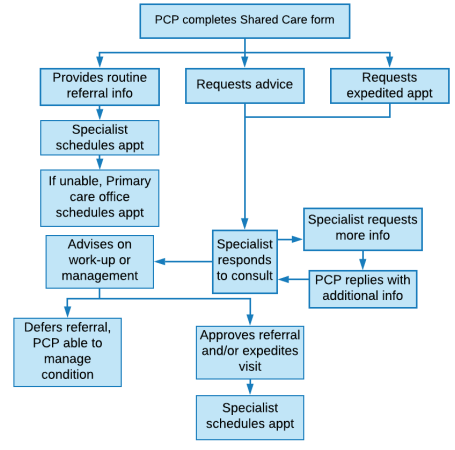
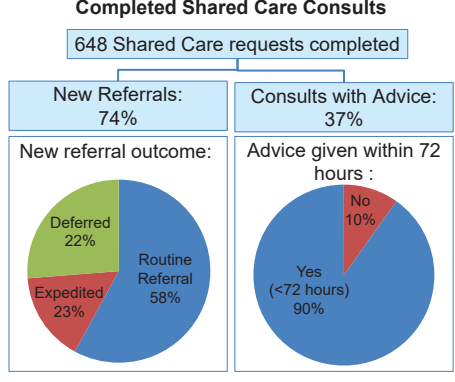


Figure 3: Functions and Outcomes of Completed Shared Care Consults



EVALUATION

Figure 4: Referral Volumes and Wait Times

Characteristic	Before Shared Care (95% CI)	After Shared Care (95% CI)	P-value
Referral Volume/month			
Neurology	12.8 (10.4, 15.3)	13.3 (11.0, 15.5)	0.799
Dermatology	17.3 (14.2, 20.4)	14.9 (12.2, 17.6)	0.170
Gastroenterology	11.3 (9.1, 13.4)	10.0 (7.9, 12.1)	0.459
Days to Completed Appointment			
Neurology	51.0 (44.4, 57.7)	51.2 (41.3, 61.1)	0.882
Dermatology	54.0 (48.0, 59.9)	59.3 (51.3, 67.3)	0.176
Gastroenterology	45.1 (37.8, 52.4)	43.1 (32.4, 53.9)	0.570
Days to Consult (appointment or advice)			
Neurology	51.0 (44.4, 57.7)	17.9 (9.4, 26.4)	<0.001
Dermatology	54.0 (48.0, 59.9)	16.5 (7.0, 25.9)	<0.001
Gastroenterology	45.1 (37.8, 52.4)	10.3 (3.8, 16.8)	<0.001

Figure 5: Referral Volumes by Insurance Status

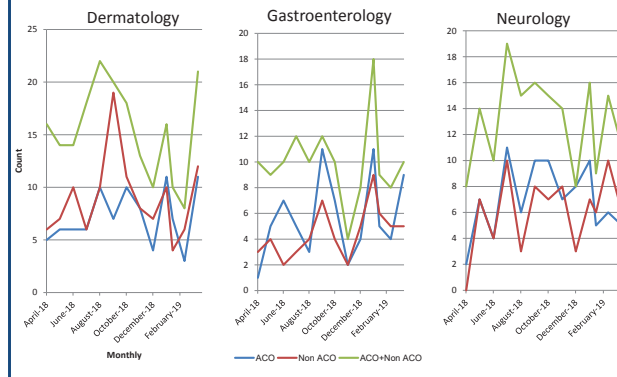


Figure 6: Primary Care Provider Survey Responses

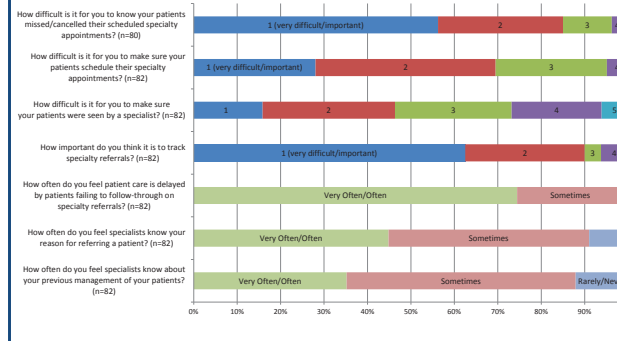


Figure 7: Caregiver Survey Responses

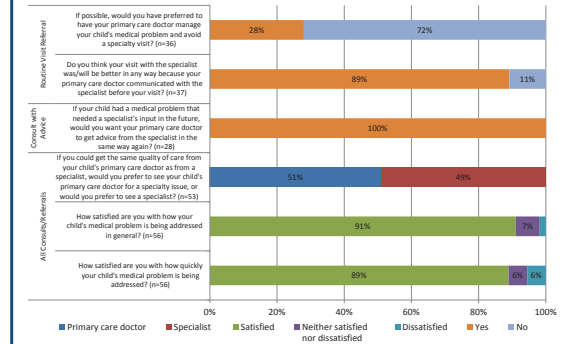


Figure 8: Caregiver Interview Excerpts

"It's nice to not have to go through and repeat yourself a hundred times... If they never spoke then I would have to start from day one what was happening versus them having all the information at their fingertips."

"I would rather get my [primary care] doctor's opinion that knows my son and then I could talk to someone that I don't know, just because I have more trust in my [primary care] doctor."

CHALLENGES AND LESSONS LEARNED

- 45% of referrals were deferred/expedited, 37% received advice, and 90% of advice given within 3 business days
- Referral volumes from PCL to Derm, GI, and Neuro remained stable
- Average wait time to first consult decreased significantly, but days to completion remained unchanged
- Caregivers and PCPs reported significant benefit from the advice function of the system
- There have been technical challenges with the tracking system and communication of referral information to specialty departments

NEXT STEPS AND SUSTAINABILITY

- On April 1, 2019, Shared Care expanded to the Endocrinology and Allergy/Immunology departments
- We plan to expand the system to other primary care clinics and specialty departments, and to continue data collection

ACKNOWLEDGEMENTS

- This work was supported by Boston Children's Accountable Care Organization. The award amount was \$191,866.50 and we anticipate spending the full amount.

BACKGROUND

In March 2018, the Department of Urology was awarded a DSRIP Innovation Grant to improve care integration for complex patients in Urology. This project focused specifically on population management in the Spina Bifida Center (SBC), the Bladder Exstrophy Program (BEP), and the Stone Clinic (SC), which care for a significant number of patients.

Patient Population	Unique Patients	MassHealth/NHP	Local Commercial Insurance
Spina Bifida Center	645	153	79
Stone Clinic	629	143	147
Bladder Exstrophy Program	208	38	30

These patients are high complexity and high utilizers of resources. **Care integration, defined as the seamless provision of health services from the perspective of the patient and family, across the entire care continuum** is essential to achieving the best health outcomes for every patient and is recognized by the AAP as the foundation for the success of ACO's.

PROJECT GOALS

- I. Integration of complex care between PCP's, urology specialists and families:
 - a. Patient Population identification
 - b. Targeted Education to support care integration
 - c. Care integration
 - i. Expand usage of Care Coordination Measurement Tool (CCMT), Pediatric Integrated Care Survey (PICS), and analytic tools
 - ii. Create a population health model
 - iii. Implement tools to support care management (Action Grid)
 - iv. Explore functionality for technology-based solutions to support population health management
- II. Connect PCP's and complex patients to urology subspecialists using technology to decrease low-value care utilization:
 - a. Connect PCPs to urology specialists
 - b. Connect high-risk patients to urology subspecialists

PROJECT TEAM

Executive Team		
Carlos Estrada, MD, MBA		
Rosemary Grant, RN		
Richard Antonelli, MD, MS		
Casey Fee, Program Director, Integrated Care Program		
Clinical Operations	Project Coordinator	
Julie Campbell, MS	Sidney Jean, BA	
Clinical Teams		
Spina Bifida Center	Bladder Exstrophy Program	Stone Clinic
Carlos Estrada, MD, MBA	Caleb Nelson, MD, MPH	Caleb Nelson, MD, MPH
Erin McNamara, MD, MPH	Joseph Borer, MD	Michael Kurtz, MD, MPH
Rebecca Sherlock, PNP - BC	Lauren Cullen, MSN CPNP	Angela Baggett, RN
Christina Lee, BA	Rosemary Grant, RN, BSN	
	Monique Joe, BA	

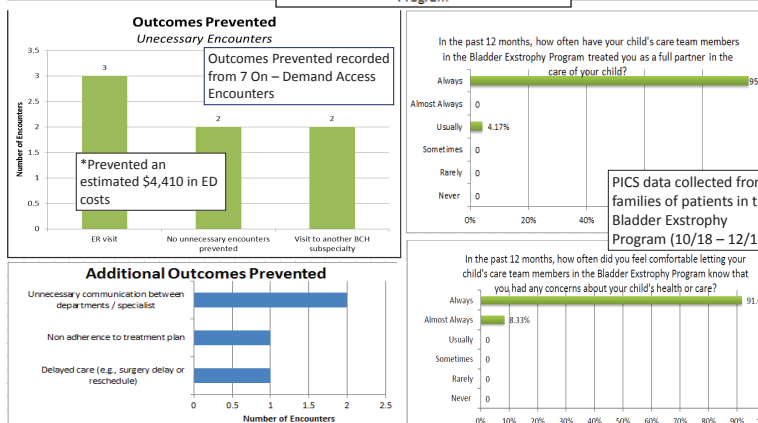
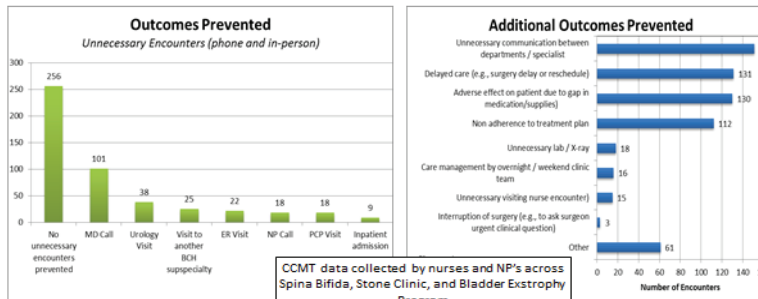
Total Awarded:
\$174,895, **Total Spent**
\$168,348

ACTIVITIES COMPLETED

Activities	Progress to Date
Patient Population Identification CCMT	<ul style="list-style-type: none"> Defined population codes for Urology clinics in BCH360 6 rounds of CCMT data collection completed by NP's and RN's in each clinic.
PICS	<ul style="list-style-type: none"> Spina Bifida Center - Launched May 2017, with data collection through July 2017 (32 responses collected) Bladder Exstrophy Program - Launched 10/2018, with data collection through 12/2018 (25 responses collected) Stone Clinic - Launched 1/2019, data collection in progress
Action Grid	<ul style="list-style-type: none"> Piloted Action Grid on paper (SBC) Prepped SIM Training format and materials
On-Demand Access Pilot Urology/PCL	<ul style="list-style-type: none"> On-Demand Access "hotlines" were established and available during regular clinic hours and "after hours" on weekdays and weekends (+1 hour after the final appointment at PCL). Hotlines were staffed by NP's and RN's across the three clinics, with support from MD's on major holidays. 7 calls received by Rebecca Sherlock, NP in Spina Bifida Center from NP's in PCL w/ 1 call from Franciscan Hospital for Children.

EVALUATION

Care Coordination Measurement Tool, data on 577 encounters



CHALLENGES & NEXT STEPS



Operational Challenges:

- On-Demand Access:** Operational challenges finding the ideal workflow to provide a direct connection between PCL and Providers in Urology.
 - The established hotlines (pager system) relied upon clinicians to sign in/out.



Technology Constraints:

- Action Grid:** Improved workflow - Clinical staff appreciates how the tool improves integration of workflows. But scalability will likely be facilitated by tech functionality in PowerChart.

"I appreciate the structure of the action grid and the information contained within it. It is ultimately a small change in work flow process that, once it becomes part of my routine practice, provides an excellent means for communication and collaboration with all members of the care team. I think the tool will allow for provision of clear expectations and responsibilities, which ultimately will empower members of the team, including the patients and families. It's a shared experience."
- Remarks from Rebecca Sherlock, NP, Spina Bifida Center on the Action Grid pilot:



LESSONS LEARNED

- Early stakeholder input and buy-in:** Across all project activities, opportunities for feedback from stakeholders were crucial to implementation and informed any necessary adjustments.
- Increasing access:** Specialty specific hotlines may not be sustainable due to staffing. However this pilot has opened up a dialogue between MD's/NP's to further explore a mechanism to be available to other providers.
- BCH Enterprise Efforts:** to improve value based, integrated care outcomes for patients with complex needs will require implementation of tools, processes and measures across all measures.

SUSTAINABILITY

- Ongoing inter-professional education and performance measurement for enhancing care integration are essential to achieve high value outcomes.
- In continuation of care integration efforts for patients with Spina Bifida, Dr. Richard Antonelli and Dr. Carlos Estrada have been recently awarded the Harvard Pilgrim Health Care Quality Grant to support: **Transforming Care for Adult Patients with Spina Bifida: An Integrated Care Approach to Transition Young Adults from Pediatric to Adult Care.**
- This project aims to transform the process by which adults and young adults can safely and effectively transition their care from pediatrics to adult care, with emphasis on cross-disciplinary care integration.



Enhancing care integration to decrease health care utilization in children with medical complexity

Glader L MD, Huth K MD MMSc, Antonelli R MD MS, Neuman M MD MPH, Starmer A MD MPH, Anderson L BS, Lenz C CPHQ, Ferullo J MSHI, Morris M BSN RN, Beagan J BSN RN, Mallick N MA, Banerjee T MPH

BACKGROUND

- Children with medical complexity (CMC) are those with chronic, severe conditions, functional limitations, high health care utilization and substantial family service needs.
- CMC utilize the Emergency Department (ED) at twice the rate of children without medical complexity.
- Gaps in knowledge exist about best practices to reduce ED utilization among CMC, with limited evidence pointing towards family education, contingency planning for acute management, enhanced communication between hospital and community providers, and ready access to health care providers as key drivers.
- This study identifies the impact of implementing these elements of care in a nurse case management model within the Complex Care Service (CCS), a consultative program at Boston Children's Hospital that provides wrap around services for CMC in collaboration with primary care providers (PCP's) and specialists.

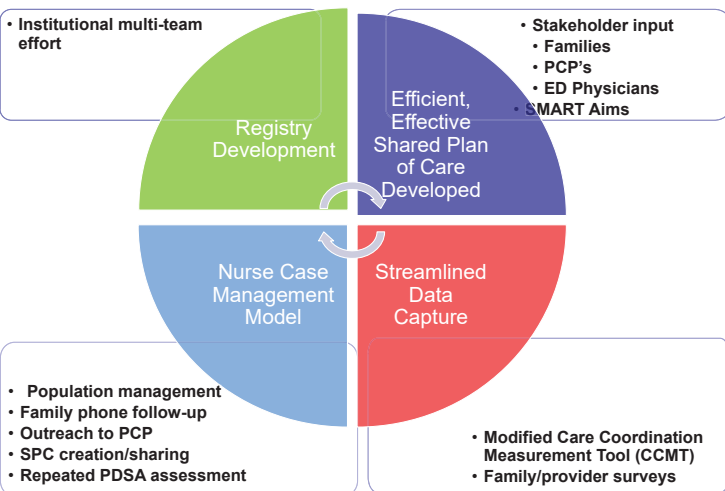
PROJECT GOALS

The objectives of this study were:

- 1) To understand stakeholder perspectives on ED utilization and possible mechanisms for reducing utilization rates;
- 2) To implement a sustainable, targeted case management model for CCS patients with recent ED utilization with the goal of reducing future ED utilization through
 - Registry development enabling population management
 - Patient education via a shared plan of care (SPC);
- 3) To measure the feasibility and impact of a post-ED visit nurse case management model on ED re-utilization for CMC.

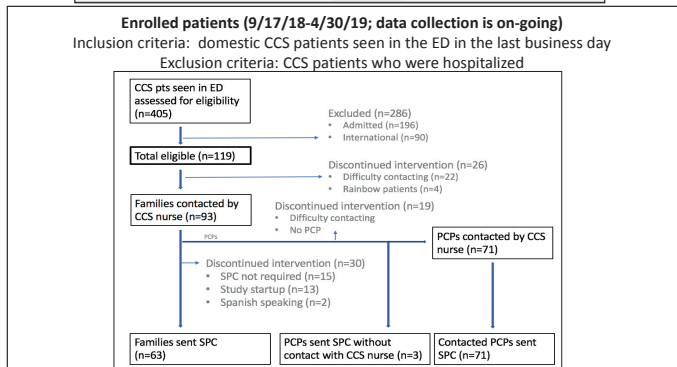
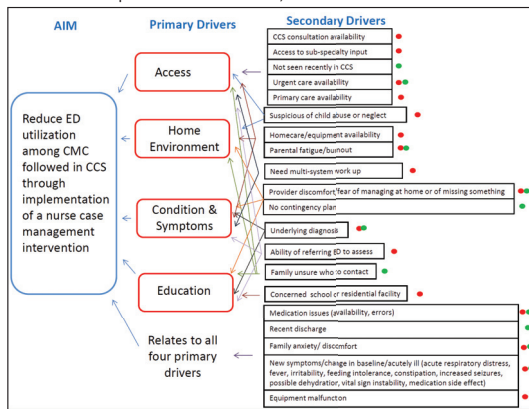
STUDY DESIGN/ACTIVITIES COMPLETED

Process for case management model development



RESULTS/EVALUATION

Input from stakeholders on key drivers for ED utilization informed intervention development. Green secondary drivers are those perceived as modifiable, red are considered unmodifiable.



Key Findings (SA = finding corresponds to achievement of a SMART Aim)	Frequency
Gaps in service identified, unmet need addressed, further care coordination required	93%
RN was able to complete SPC for families when SPC was indicated (SA)	83%
RN was able to complete SPC for primary care practices (SA)	79%
Caregivers who felt that the intervention was beneficial specifically reported improved capacity for acute symptom management at home (SA)	74%
RN could address patient needs independently	71%
Visits were perceived by the RN as possibly preventable had the family called before going to ED	13.5%
RN perception of preventing repeat ER visit	13%
Improved medication treatment adherence	11%

Comparison of ED re-utilization pre and post-intervention

	3 day revisit rate/100 patients $\left(\frac{\# \text{ patients with a 3day ED revisit} \times 100}{\# \text{ patients with an index ED visit}} \right)$	7 day revisit rate/100 patients $\left(\frac{\# \text{ patients with a 7day ED revisit} \times 100}{\# \text{ patients with an index ED visit}} \right)$
Pre-intervention Q4 2017 + Q1 2018	2.1	4.6
Post-intervention Q4 2018 + Q1 2019	2.6	4.0
p value	NS	NS

CHALLENGES AND LESSONS LEARNED

- Creating the registry required institutional collaboration among multiple teams and substantial communication.
- Initial concepts around the SPC were more complex than the final version settled upon. It was necessary to create a model that was both efficient and within scope of practice for an RN to be feasible and sustainable.
- Documentation was initially cumbersome. Once systems were established documentation became smoother. This has ultimately allowed creation of a streamlined system that is sustainable.
- While immediate feedback associated with RN outreach to the PCP was consistently very positive around enhanced sense of collaboration and offices expressed appreciation of the SPC, attempts to conduct formal follow-up surveys with PCP offices related to the intervention were limited in success due to the busy nature of primary care offices.

NEXT STEPS & SUSTAINABILITY

- Daily registry pulls regarding ED utilization and admission are on-going.
- Post-ED nurse case management phone calls and creation/dissemination of SPC's have become a standard of care in CCS.
- An analogous model of care is spreading to include hospital post-discharges.
- An active patient education initiative is being developed to encourage early contact with CCS for acute clinical concerns prior to coming to the ED in an effort to target reduction in ED utilization.
- Assessment of ED staff perspectives on preventability of CCS patient admissions along with deeper registry-based evaluation of reasons for ED presentation may further inform outpatient systems of CCS care supporting acutely ill patients.
- There is active evolution of multiple broad population management strategies utilizing the newly developed registry.

FUNDING STRUCTURE

Awarded: \$ 191,747.00 through the ACO Innovation Grant Fund Program
Anticipated spend: full amount



Introduction

- Pediatric chronic pain impacts 25-46% of children in the U.S. and accounts for \$19.5 billion dollars in direct annual healthcare costs¹.
- Cognitive behavioral therapy is an evidence based treatment for pediatric pain, but access to this treatment can be difficult.
- The Comfort Ability Program (CAP) is a one-day, cognitive behavioral and psychoeducational workshop for adolescents (ages 10-17) with chronic pain and their parents, and has already demonstrated feasibility and acceptability².
- This study assesses the association between the program and chronic pain related healthcare expenses, functional disability, pain catastrophizing, and pain self-efficacy. **This study is only partially complete; analyses are not yet fully powered.**

What is The Comfort Ability Program?



The Comfort Ability Program (CAP) is a manualized clinical intervention that introduces cognitive, biobehavioral, and parent-training pain management strategies. This one-day intervention consists of a parent group and an adolescent group and is currently licensed to 16 children's hospitals in the United States and Canada.

Financial Information

Our award from the Boston Children's Accountable Care Organization (ACO) consisted of \$105,150.00 for the period beginning on January 1, 2018 and ending on December 31, 2018. While our study is not yet complete, we have spent the full amount that was received by the ACO to ensure that we have the materials and participant incentives that are necessary in order to continue this study to completion.

Objectives

1. Evaluate direct and ancillary healthcare costs that are associated with pediatric chronic pain for individuals attending The Comfort Ability as well as families who were referred to, but did not attend The Comfort Ability.
2. Identify emerging differences at baseline and 30-day follow-up within our treatment and control groups.

Methods

Study Sample

Our preliminary results are based on a treatment sample of 68 adolescents and 68 parents who attended CAP at Boston Children's Hospital between July 2018 – March 2019. They completed surveys at baseline and 30-day follow-up. The control sample included 48 adolescents and 57 parents who were referred to CAP, but did not attend. They also completed surveys at baseline and 30-day follow-up. **In total, to fully power our analyses, we will continue recruitment until we reach 120 adolescent and parent dyads for treatment and control.**

Measures and Analyses

Adolescent participants completed the Functional Disability Inventory (FDI)³, Pain Catastrophizing Scale (PCS)⁴, and Pediatric Pain Screening Tool (PPST)⁵ at baseline assessment and 30-day follow-up. Parent participants completed the Adult Responses to Children's Symptoms (ARCS)⁶, Pain Self-Efficacy Scale (PSES)⁷, a parent proxy version of the PCS⁸, and healthcare utilization questionnaires about out-of-pocket healthcare expenses at baseline and 30-day follow-up. One-sample paired sign tests were used to conduct within group comparisons at baseline and 30-day follow-up.

Preliminary Results

Table 1. Demographics and Baseline Characteristics of Adolescent Participants

	Control (N = 48)	Treatment (N = 68)	p-value
Age, Mean (SD)	14.6 (2.5)	14.5 (2.3)	.785
Sex – Female, n (%)	36 (75.0)	53 (77.9)	.930
Ethnicity – Caucasian/White, n (%)	40 (83.3)	58 (85.3)	.774
Primary Pain Problem, n (%)			.056
Headache	10 (20.8)	15 (22.1)	
Abdominal/Gastrointestinal Pain	11 (22.9)	17 (25.0)	
Hypermobility/EDS (Joint Pain)	2 (4.2)	7 (10.3)	
Complex Regional Pain Syndrome	3 (6.3)	4 (5.9)	
Nerve Pain	6 (12.5)	18 (26.5)	
Widespread Musculoskeletal Pain	5 (10.4)	1 (1.5)	
Other Pain	10 (20.8)	5 (7.4)	
Secondary Pain Problem, n (%)	20 (41.7)	29 (42.7)	.074
Pain Duration, n (%)			.417
Less than 1 year	12 (25.1)	25 (36.8)	
Between 1- 3 years	21 (43.9)	20 (29.5)	
Greater than 3 years	14 (29.3)	23 (33.8)	
Currently in Physical Therapy, n (%)	9 (19.2)	35 (51.5)	<.001
Pain Intensity (VAS), Mean (SD)	61.6 (23.5)	72.5 (13.1)	<.01

Table 2. Results from Adolescent Respondents for Baseline Assessment and 30-day Follow-up

	Control_B (N = 48)	Control_30 (N = 30)	p-value	Treatment_B (N = 68)	Treatment_30 (N = 44)	p-value
FDI, Mean (SD)	16.5 (12.6)	15.7 (13.2)	.557	23.0 (11.3)	17.3 (11.3)	.499
PCS, Mean (SD)	23.9 (11.8)	21.7 (14.5)	.557	23.2 (11.4)	19.5 (11.1)	.871
PPST, Mean (SD)	4.2 (2.7)	4.0 (2.7)	.405	5.7 (2.0)	4.3 (2.6)	<.01

Table 3. Results from Parent Respondents for Baseline Assessment and 30-day Follow-up

	Control_B (N = 57)	Control_30 (N = 32)	p-value	Treatment_B (N = 68)	Treatment_30 (N = 47)	p-value
ARCS, Mean (SD)	13.6 (11.0)	12.5 (10.9)	.701	13.8 (10.6)	10.1 (8.6)	<.01
PCS, Mean (SD)	24.1 (16.6)	23.2 (16.5)	.557	23.6 (15.3)	20.0 (15.0)	<.05
PSES, Mean (SD)	20.8 (8.1)	18.7 (8.5)	<.01	19.9 (8.5)	16.2 (8.1)	<.001
Hours Missed From Work (Previous Four Weeks), Mean (SD)	15.6 (6.3)	13.2 (7.0)	.146	12.4 (4.8)	18.4 (8.9)	.541
Out of Pocket Healthcare Costs (USD \$), Median [IQR]	56 [10 – 200]	351 [10 – 208]	.215	201 [28 – 660]	53 [10 – 535]	<.05

Adolescent participants were predominantly female, presented most frequently with headache, abdominal, or nerve pain, and reported these symptoms were present for 1 – 3 years. There were significant differences at baseline between our treatment and control group for involvement in physical therapy and pain intensity (treatment group > control). Final project analyses will need to account for these differences.

Adolescent participants in the treatment sample demonstrated a significant decrease in pain severity (24.6%, PPST: $p < .01$) between baseline and 30-day follow-up. Adolescent participants in the treatment sample also demonstrated a 24.9% decrease in functional disability scores, and a 16.0% decrease in pain catastrophizing scores from baseline to 30-day follow up, though these did not reach statistical significance. Adolescents in the control sample had no significant differences between baseline and 30-day follow-up.

Parent participants in the treatment sample demonstrated a significant decrease in solicitous responses to their child's symptoms (26.8%, ARCS: $p < .01$), pain catastrophizing (15.3%, PCS: $p < .05$), and out-of-pocket healthcare expenses during the previous 30 days ($p < .05$) when comparing the baseline assessment and 30-day follow-up.

Parent participants in both the treatment and control samples also demonstrated a significant improvement in pain self-efficacy (Control: 10.1%, $p < .01$; Treatment: 18.6%, $p < .001$). Neither sample demonstrated significant differences in hours missed from work in the previous four weeks when comparing baseline to 30-day follow-up.

Preliminary Conclusions

- The characteristics of both samples are consistent with general prevalence rates.
- Baseline differences between the control sample and treatment sample suggest that families may be more motivated to participate in CAP if adolescent pain severity is greater and physical therapy is already in place.
- We observed significant within-group improvements in the PPST for adolescents in the treatment sample from baseline to 30-day follow-up.
- Within-group analyses for the parent treatment sample demonstrated a significant reduction in solicitous parent responses, pain catastrophizing, and out-of-pocket healthcare expenditures from baseline to 30-day follow-up.
- Both the parent treatment group and parent control group demonstrated a significant improvement in pain self-efficacy from baseline to 30-day follow-up.

Summary of Results

Demonstrating economic and clinical viability for an intervention can help promote dissemination and improve clinical outcomes. Our preliminary results demonstrated a significant decrease in out-of-pocket healthcare expenses for families that attended CAP. In our limited sample, parents replicated significant clinical improvements postintervention in several areas that were initially demonstrated in our initial feasibility study². Our full sample is required to further understand the effects that this intervention has on healthcare utilization and expenses related to pediatric chronic pain. When we have collected our full sample, we will investigate these outcomes after 90 days post-intervention, in addition to examining potential differences between our control group and treatment group.

Challenges and Lessons Learned

- We expected that we would be able to recruit 120 adolescent/parent dyads for both the treatment and control group in the initial timeframe specified by the ACO. To meet our target sample for the treatment group, we proposed that we would conduct multiple intervention sessions per month, whereas we usually only conduct one intervention per month. However, we encountered challenges with staffing and enrolling sufficient participants for more than one group per month. Because of this, we reverted to conducting the workshop on a monthly basis.
- Enrollment for the control group has been slower than we anticipated. To adjust for this, we amended our initial protocol to allow for additional methods to recruit participants for the control group.

Future Direction and Sustainability

The Comfort Ability Program (CAP) was designed to be accessible by underserved populations with limited access to behavioral health interventions. The clinical intervention is growing on both a national and international level; six US-based children's hospitals sites have adopted CAP in the previous 12 months, with planned expansion into Canada and Australia. Our program has also received departmental support to facilitate the program's growth. Ongoing clinical assessment and research is needed to inform expectations for patients and referring providers.

References

References have been provided in a supplemental attachment, but can also be provided by contacting Taylor Turrisi at taylor.turrisi@childrens.harvard.edu.



Bringing the ICU Home: A Community-based Care Model for Children with Chronic Respiratory Failure

Robert J. Graham, MD with C.A.P.E. and Home Ventilation Program

Objectives:

This proposal addressed the Complex Care clinical priority for the Boston Children's Hospital Accountable Care Organization (BCH ACO) but also targeted Social Determinants of Health and Behavioral Health priorities, recognizing the challenges in access to care and the relationship between HRQL and resource utilization. Overall, **we seek to demonstrate immediate cost savings in a high-risk, high-cost pediatric population by maintaining specialized hospital-based services in patient homes.** These efforts built upon an established program, Critical Care, Anesthesia, and Perioperative Extension (CAPE) and Home Ventilation Program. CAPE was previously supported by grants and currently, is significantly subsidized by the Department of Anesthesia, Critical Care and Pain Medicine, as reimbursement from the traditional fee-for-service (FFS) system does not meet program costs, allow for scaling, adaptation of services, or replication.

Background:

Children with chronic respiratory failure (CRF) and technology dependence represent a small and isolated population but constitute the highest cost strata within pediatrics and among the highest in all health care. Notably, these costs are extremely prolonged, often extending over decades. Prior analysis of BCH inpatient hospital utilization for a cohort of approximately 200-250 CAPE patients revealed charges >\$10 million annually, although there was no individual cost persistence by patient.

Care coordination for this vulnerable group of children remains suboptimal and is too often left to emergency providers. Much of the incurred cost is related to preventable hospital care, primarily in the ED and ICU. Nationally, children with any degree of technology dependence are at 373 times greater risk of requiring an ICU admission compared to a previously healthy child. A national study of critical care admissions between 1997-2006 found an increasing proportion of children with comorbid conditions (35% up to 41% of all ICU admissions) and consistent twofold high accrued charges in comparison to children without prior conditions. Higher severity of illness, longer ICU stays, and longer hospital admissions are predictive of decreased adherence with outpatient appointments independent of socioeconomic or demographic risk-factors.

Project Goals / Interventions:

1. Describe program costs and savings implications. All program activities and resultant clinical outcomes were tracked using an adapted version of the Care Coordination Measurement Tool® (aCCMT). Patient characteristics, program activity, and acute care resource utilization were prospectively documented in the aCCMT and retrospectively cross-validated with hospital billing data.
2. Implementation of an innovative, 8-week randomized, cross-over telemental health (TMH) initiative with cognitive behavioral therapy for parents to optimize response to stress and parental HRQL, including PROMIS-29, PROMIS Global Health, CHRIS, Fidelity form, and modified CAHPS.
3. Extend prior outcomes efforts from FY 2012-14 to 2015-2018 and propose economic models for scaling, sustaining, and replication of efficient and effective, quality clinical programs with a focus on ACO enrollees.

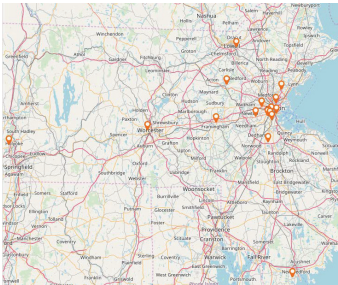
ACO / DSRIP Support:

Total Budget = \$262,500 (100% expended)
 -Staffing (no new hiring): Allocation of \$222,500 to support ¼ FTE respiratory therapist, 1 FTE social worker for TMH and routine care provision, 1FTE program coordinator.
 -Statistical support and modeling: Allocation of \$40,000 for services of Susan K. Parsons, MD, MRP, Institute for Clinical Research and Health Policy Studies (ICRHPS).
 -In kind contributions Michael McManus, MD, MPH (BCH) for care model development and Joanne Corbin, PhD (Smith College) for collaborative oversight of TMH.

Program Provision and Outcomes (March 1, 2018 – February 1, 2019):

- 22 enrollees (3 new patients following interim report)
- Primary Dx: Prune Belly Syndrome, SMA (4), ROHHAD, Myelomeningocele, CLD Prematurity (2), Congenital Myasthenia, Various encephalopathies, Multifactorial respiratory failure
- Age Range: 1 to 17 years, Median age: 6.59 years old
- Race: Asian 9%, White 13%, Black 5%, Hispanic 50%, Other/Will Not Disclose 23%

• Encounters 402 total (>18 per patient)



Encounter Type	Count
Clinic	14
E-Mail	102
Home Visit	27
Inpatient	52
Non-Clinic Outpatient	7
Telephone	200

Selected Outcomes Occurred	Count
Early Discharge	1
Ordered Prescriptions, Equipment, Diapers, Taxi, etc.	132
Reconciled Discrepancies	22
Referral for Pediatric Sick Visit	3
Referral to ER	3
Referral to Lab/X-Ray	1
Referral to Specialized Therapies	3
Referral to Subspecialist	5

Outcomes Prevented

ER Visit	7
Hospitalization	1
Lab /X-Ray	5
Subspecialist Visit	5
Unnecessary Prescription/Medication	5
Visit to Pediatric Office/Clinic	33

Hospitalizations

- 14 admissions (6 patients), 0 Deaths
- Total hospitalization days 115.13, Average LOS – 8.2 days (Max- 19, Min- 1.6)
- Reasons for admissions:
 - Patient 1 (Severe HIE, trach vent dep)– Acute on chronic respiratory failure with lower airway disease as well as complex tracheal obstruction, hyperthermia, and autonomic storming x 2
 - Patient 2 (Tri 21, TEF, Pulm Htn, Trach and vent) – Adenovirus ARDS
 - Patient 3 (Tri 21, Pulm Vein Stenosis, Trach and vent) – Acute on chronic resp failure x 2, scheduled cardiac cath x 2, anemia with GI bleed and multifactorial issues x 3
 - Patient 4 (Complex lymphatic malformation and CLD) – Scheduled surgery
 - Patient 5 (ROHHAD) - Sepsis
 - Patient 6 (Premature CLD, PulmHTN) – Acute on chronic resp failure, culture negative
- New patients or re-enrollees patients history prior to CAPE involvement
 - Infant Premie CLD – 5 admits (resp) in 6 mo – needed vent support; School age with myelo & vent - 3 admits (Neuro/Resp) in 6 months; Adult with CP & Trach – RSV+

Telemental Health (TMH) Provision and Outcomes:

*Eligibility defined as parent baseline score of < 4 Std. Dev. on CHRIS HRQoL screener
 *All participants provided with hardware and software to engage in TMH

Parents screened for study:	150
Parents eligible:	75
Parents deemed ineligible :	20 (already receiving mental health services)
Parents enroll in the study:	30 (11 in ACO)
Parents who withdrew from study:	14
Child's death (n= 3)	
Parent hospitalization (medical and mental health) reasons (n= 2)	
Did not complete intervention on time (n=7)	
Passive refusal (n=2)	
Parents who completed study:	16 (9 in ACO)

Summary of TMH Analysis Conducted (Mixed-Design ANOVAS)

Survey Item	Baseline	Pretest	Posttest	Follow-up	F	p	Effect Size (η ²)
Patient Health Questionnaire – Depression (Lower = less depression)	8.25	10.223	9.07	1.77	39.3	<.001	.737
Generalized Anxiety Disorder (lower = less anxious)	8.88	8.18	8.99	8.99	18.3	<.001	.585
Lubben Social Network – family support (higher = more support)	12.37	12.97	12.17	12.33	1.10	.361	.073
Lubben Social Network – friend support (higher = more support)	9.88	9.93	9.95	10.10	.360	.782	.025
Global Health Scale (GHS) – sleep and fatigue (higher = greater health)	15.88	15.67	16.60	16.63	2.31	.090	.142

Long-term economic evaluation and modeling:

- Area Deprivation Index (see figure) for CAPE pts in ACO=6 and non-ACO=5
- Persistent high year-to-year acute resource utilization and associated cost
- Cost concentration - Top 10% of utilizers accounted for 47-51% of charges
- Highly variable individual acute resource utilization, independent of insurer, ACO, Medicaid, Medicare, or private payor
- Historical (FY12-14) 30-day readmission rates of 21-28%

	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017
C.A.P.E. Continuity Patients (excluding consult or Seven Hills Long-term Care), n	218	238	240	245	242	282
Encounters, n	2069	2893	3472	3373	2253	3233
Encounters per Patient, Median (q1, q3)	5(2.12)	7(3.17)	9(3.22)	10(3.19)	6(3.12)	8(3.18)
ACO pts pre-ACO history) Encounters per pt (q1, q2)				20(10.29)	8(6.13)	17(7.19)
Patients with Admission, n	114	115	121	104	102	88
Number of Admissions	281	305	277	210	194	211
Sum of Inpatient Charges	\$20,918,271	\$27,507,778	\$17,294,203	\$11,897,708	\$17,717,241	\$13,000,709
Outgroup Medication Costs				(\$2,469,793)	(2,187,703)	(\$4,098,001)
ACO pts pre-ACO history) Admissions, \$				12 pt, 8 Adm (\$283,809)	10pt, 5 Adm (\$249,717)	23 pt, 10Adm (\$1,406,660)

Conclusions:

1. Children with chronic respiratory failure (CRF) and technology dependence utilize extensive outpatient and inpatient services. Care coordination service needs are extensive and require a multidisciplinary team with potential for mitigation of some acute care service requirements.
2. Telemental health services for parents of children with CRF are feasible. Efficacy measures identified significant improvement in anxiety and depression amongst participants. Social isolation and physical/fatigue markers were not altered. Findings speak to modifiable family impact of CRF with implications for healthcare utilization.
3. Children with CRF and technology dependence account for multi-million dollars in healthcare expenditure. There is no individual cost persistence or prediction from year to year, but cohort utilization is consistent.

- Comprehensive care services are required to meet child and family needs in this high risk population. Healthcare utilization is extensive but modifiable. Current FFS models do not allow such programs to scale or adapt services. ACO PMPM models may require exemptions for high risk cohort, such as children with CRF. Parent-targeted interventions and care coordination hold potential for long-term improvements in HRQoL and cost but require additional infrastructure.