SAFER
The Chair’s Initiatives of the Department of Pediatrics

ROUND 3
2011 – 2013

The Children’s Hospital of Philadelphia® | Hope lives here.®
As one of the top pediatric hospitals in the world, The Children’s Hospital of Philadelphia is populated by extremely bright, innovative and motivated physicians, nurses and other professionals. They often have great ideas to improve patient care and safety — but need funding and other resources in order to get those ideas off the ground. The Chair’s Initiatives of the Department of Pediatrics is an internal grant program that provides two years of seed money, collaboration and support to teams as they tackle some of the toughest problems in healthcare.

The 22 teams funded since the program’s inception in 2006 have established a track record of excellence and accomplishment. They have:

• traveled around the country and the world to give presentations at more than 175 conferences and other events for colleagues in healthcare, as well as parents, school staff and others
• published approximately 90 articles in respected journals related to their initiatives
• received 27 grants worth approximately $7.4 million to further their efforts after Chair’s Initiatives funding ended
• been featured in hundreds of national and international news stories

Most notably, they have found ways to provide better, safer care for children and their families. This booklet provides details about the accomplishments of Round 3 of the Chair’s Initiatives.

The six projects selected for the third round of Chair’s Initiatives were funded from 2011 to 2013 and continued the history of excellence.

**Minds Matter: Improving Pediatric Concussion Management** (page 2)
Defining guidelines for concussion care in emergency rooms, primary care practices, sports medicine and other settings

**Assuring Quality and Safety at CHOP Community Pediatric Programs** (page 4)
Implementing a system to ensure that care at CHOP-affiliated units and programs at local hospitals is as excellent as at CHOP

**A Shared Decision-making Portal for Pediatric Chronic Illness** (page 6)
Designing a computer portal shared by parents and clinicians to improve communication and care for asthma

**Improving Hospital Care for and Service Delivery to Individuals with Autism Spectrum Disorders** (page 8)
Finding better ways to communicate with and care for patients with autism

**Preventing Outpatient Central Line-associated Bloodstream Infections** (page 10)
Reducing the at-home incidence of one of the most costly problems in healthcare

**Transitioning from Pediatric to Adult Services: A Primary-care-based Model** (page 12)
Helping young people with chronic illness move to — and stay with — adult primary care providers
Minds Matter: Improving Pediatric Concussion Management

Challenge
Every year thousands of children and adolescents suffer concussion. In recent years, awareness of concussion has grown rapidly, and visits to the doctor for suspected concussion have increased dramatically.

Care for concussion may be provided by multiple teams, including emergency room staff, primary care pediatricians and sports medicine physicians. This can result in fragmented care and inconsistent advice, and the child may not receive the proper follow-up care.

With Chair’s Initiatives funding, a team set out to improve care for children and adolescents with concussion by creating tools to standardize and streamline management of concussion in the CHOP Care Network, and to educate parents and patients.

Team
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Accomplishments
- The team created a tool in CHOP’s electronic medical record system to help primary care physicians evaluate concussion. The tool is now widely used in CHOP-affiliated primary care practices.
- The team created a website, www.chop.edu/concussion, with information for parents, kids, school staff, coaches and healthcare providers. Visits to the site average 3,000 per month.
- The team held a conference for healthcare providers and school staff, providing information on the basics of concussion care. Nearly 160 attended. The second annual conference will be held in April 2014.
- Many calls from parents about concussion were coming in to CHOP’s After Hours Program call center. The team trained nurses who staff the call center in triaging suspected concussion.
- The team updated a “head trauma pathway,” a computer guideline for care widely used by CHOP Emergency Department staff, to include concussion-specific information.
- The team began to define parameters for a concussion registry, a database of information about concussion cases that will inform scientific research to improve care.
- To date, the team has seven peer-reviewed publications, and has completed more than 20 presentations at scientific gatherings and more than 40 presentations at community events.
# Minds Matter: Improving Pediatric Concussion Management

## Department of Pediatrics Chair’s Initiatives

### Project Goal

To develop a comprehensive pediatric concussion management program throughout the CHOP Network by creating an evidence-based tool-kit that will streamline pediatric concussion care Network-wide.

### Implementation/Accomplishments

1. **Epic Smart Set and Trainings:** May-July 2012
   - 5 sessions trained CHOP primary care providers in concussion management including use of newly created Epic SmartSet (released in July 2012) for evaluating patients with suspected concussion; follow-up training in November 2012
   - Trained nearly 100 primary care clinicians from across the CHOP care network, including one designated “Concussion Champion” from each care network location.

2. **Website:** www.chop.edu/concussion
   - Phase 1: June 2012 centralized all of the concussion information on the newly created www.chop.edu/concussion; uploaded information throughout the CHOP web was removed.
   - Phase 2: April 2013 included sections specific to families, healthcare providers, school staff and coaches, and will be supplemented with multimedia content, including Q&A videos in Summer 2013.

3. **CME Conference:** April 6, 2013: April 2014 conference scheduled in collaboration with PAHS
   - Standing room only crowd of nearly 160 (representing 8 states and 2 countries) for the 1st Annual “Diagnosis and Management of Child and Adolescent Concussion: A Primer for Primary Care Providers and Educators” conference. The standing event included 15 sessions for clinicians and educators ranging from “Standard Concussion Treatment” to “Concussion in the Classroom”.

4. **After Hours Program:** September 2012
   - Updated the After Hours Program call center telephone triage guidelines for head injury to align them with the CHOP concussion management guidelines.
   - Trained the triage nurse on the new guidelines and have continued to work with the After Hours Program to further improve the guidelines.

5. **Materials:** Patient Family Education (PFEs) and ED Head Trauma Pathway
   - May 2012 updated CHOP Emergency Department’s Head Trauma Pathway with concussion-specific information.
   - June 2012 released 2 FPEs: “Understanding your Child’s Condition Facts About Concussion” & “Helping your Child Recover—Coping After a Concussion.” Available online at the website and the intranet, integrated into the Epic Smartset and the Emergency Department’s discharge instructions.

6. **Follow-up funding:** received follow-up funding for continued activities
   - CHOP Women’s Committee, NLT Lacrosse/Philadelphia Wings Lacrosse, UPenn T1MAT program

### Challenges/Barriers/Next Steps

- Clinical demand greater than currently available resources
- Best practices still evolving; need to provide ongoing education to primary care to maximize their concussion management practices
- Science is incomplete; need for pediatric research, and CHOP can play a prominent role based on volume and expertise

### Project Measures and Tools

#### Primary Care

- **Primary Care Concussion Visits**
  - Total visits FY05-13: 7,319 visits
  - Concussion chart at each Care Network Site
  - Targeted, hands-on training
  - New Epic SmartSet used: 3,192 times in 10 months
  - 67% of those diagnosed with concussion at primary care used Epic SmartSet

#### Specialty Care

- **Specialty Concussion Visits**
  - Total visits FY05-13: 12,810 visits
  - Concussion registry specifications defined
  - Obtained partial hospital funding for concussion nurse practitioner who coordinates care

- Trained all 23 After Hours triage nurses
- Head Trauma Triage Guidelines Updated, used 1,661 times in 8 months
- 52% of patients who were seen within 24 hours, as directed, received diagnosis of concussion

### Publications & Presentations

- **Peer-reviewed Publications:** 7 (2 in press)
- **Scientific Presentations:** >20
- **Community Presentations:** >40

<table>
<thead>
<tr>
<th>Publications</th>
</tr>
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<tbody>
<tr>
<td>3. Pediatric Annual Special Issue on Concussion (Guest Editor)</td>
</tr>
<tr>
<td>6. Pediatric Annual Special Issue on Concussion (Guest Editor)</td>
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</table>

## Selected Scientific Presentations

Challenge
As healthcare has evolved, most major institutions have grown far beyond the walls of the original hospital. How can care be standardized and measured across multiple sites, to ensure the patient receives the highest quality, safest care no matter the location?
As part of its Care Network, The Children’s Hospital of Philadelphia provides staff for pediatric care at several community hospitals, including emergency department care, general pediatric care, and neonatal intensive care. With Chair’s Initiatives funding, this team set out to define, test and implement a system to monitor the quality of care in CHOP programs at community hospitals. The end goal: to ensure that care at every CHOP site is as excellent as care at the Main Campus.

Accomplishments
• The team identified 13 metrics to measure quality of care at community sites, in emergency medicine, general pediatrics and neonatology. For example, one metric measures the time it takes for a child with asthma who comes to an emergency room to receive a steroid medication. Another measures the incidence of a certain type of bloodstream infection in neonates.
• Eighteen practices within 10 community hospitals began to track the metrics at their sites.
• The team began creating a system for a central collection site for data from all locations, accommodating varying computer systems and methods of data collection.
• Each site now routinely analyzes data, and the sites (grouped by specialty) confer to discuss data and methods for improvement.
• The team continues to analyze data to determine whether the implementation of a monitoring system has improved care. Because some trends in the metrics are cyclical, analysis becomes more meaningful with time.
Assuring Quality and Safety at CHOP Community Pediatric Programs
Department of Pediatrics – Chair’s Initiative

Jan Becswinkel, Brandon Calderon, John Chuo, Jeff Gordes, Carrie Hulmel-Miller, Debbie McKetta, Karen Pinsky, Jeff Seiden, Kathy Shaw, April Taylor

Objective
To design, test and implement a quality monitoring system to ensure that pediatric care delivered throughout the CHOP outreach network meets the highest quality standards through standardization of practice and data transparency.

Accomplishments
1. Thirteen quality metrics defined based on existing pathways, clinical guidelines and practices at CHOP Main within the divisions of Emergency Medicine, General Pediatrics and Neonatology.
   • Eighteen clinical practices within 10 community partner hospital sites actively track the defined metrics.
2. RedCap online database successfully implemented with central data submission, collation and reporting across all community partner hospital sites. Site-by-site comparison of metric performance and overall sub-specialty average performance reviewed monthly.
   • Qlikview “real-time” automated report system developed and currently in final round of pilot testing.
3. Infrastructure created within each sub-specialty area to routinely analyze data and assess improvement across community partner hospital sites. Sub-specialty areas have instituted regular network conference calls to discuss quality and patient safety data and initiatives.
4. Early reports suggest that ongoing assessment and data transparency at partner community hospital sites has led to improved performance.
   • Neonatology has used the network data to identify vulnerable areas of care for each community partner hospital. Areas of concern are given an importance factor (based on how often the item is identified as an area of concern) and impact factor (based on the actions taken). Identified concerns have led to actions which improved patient care management, communication, monitoring and many other areas.

<table>
<thead>
<tr>
<th>Quality Metrics</th>
<th>Metrics by Specialty:</th>
</tr>
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<tbody>
<tr>
<td>Emergency Medicine</td>
<td>General Pediatrics</td>
</tr>
<tr>
<td>Time to Abx: Febrile Neonate</td>
<td>Asthma Care Plan</td>
</tr>
<tr>
<td>Time to Steroid for Asthma</td>
<td>Antibiotic Use for Bronchiolitis</td>
</tr>
<tr>
<td>UTI Pathway Compliance</td>
<td>Gastroenteritis LOS</td>
</tr>
<tr>
<td>Head CT Utilization Rate</td>
<td>Febrile Infant LOS</td>
</tr>
<tr>
<td>Medication Error Rate</td>
<td>Medication Error Rate</td>
</tr>
</tbody>
</table>
Challenge

Screen-time is a big part of nearly everyone’s life now, as laptops, tablets, phones and other iterations of the computer continue to proliferate. Finding effective ways to use these tools to improve healthcare is complicated — and important.

With Chair’s Initiatives funding, this team set out to design and test a computer portal for the families of children with asthma. The tool could be used to educate families, track symptoms between visits, and boost communication between the family and their primary care pediatrician. The end goal: to improve the health of children with asthma.

Team

Alexander Fiks, M.D., M.S.C.E.
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Trude Haecker, M.D.
Peter White, Ph.D.
Dean Karavite, M.S.
Elena DeBartolo
Stephanie Mayne, M.H.S.
Ryan J. O’Hara
LeMar Davidson, M.S.

Accomplishments

- After a survey of nearly 60 parents, pediatricians and others, the team designed a working portal called MyAsthma Portal.
- The portal was implemented at three primary care pediatric practices, with 30 families participating.
- The portal helps parents and children define goals that can guide asthma care.
- Based on input from the parents about severity and timing of symptoms, the portal alerts the parent and the pediatric practice when asthma is poorly controlled, and the practice calls the parents to ensure appropriate steps are taken.
- The team is evaluating whether the portal improved care, using the 30 families in the pilot program and 30 control families (who didn’t use the portal). Measures include whether emergency department visits and hospitalizations declined among patients who used the portal, and whether treatment adherence and goal attainment rose.
- The team plans to use MyAsthma Portal as a basis for developing a portal for ADHD and other conditions.
- The team has received a grant that will allow the portal to be tested in a much larger pilot program, nationally.
A Shared Decision Making Portal for Pediatric Chronic Illness

Department of Pediatrics Chair's Initiative

Project Goal
1. To develop and test an electronic medical record-based shared decision making portal that engages families and clinicians in the care of pediatric chronic illness.

Interventions and Accomplishments

Stakeholders Interviewed: Total
Parents 2
Pediatricians 8
Nurse Practitioners 6
Other Nurse 17
Clinical Pharmacists 1
Chief of Compliance 1
Attorneys 1
Risk Management 1
TOTAL 58

Top 5 Accomplishments:
1. Designed a working portal based on user specified needs.
2. Successfully implemented the portal at three sites.
3. Time saved by parents and their children.
4. Portal has identified poor asthma control between office visits.
5. Results were automatically sent to the patient and offered follow-up by MyChart message or phone call.

Performance Measures

- Goal Attainment
- Treatment Acceptability
- Improved Clinical Outcomes of Pediatric Asthma
- Coordinated Care
- Treatment Adherence
- ED Visits
- Hospitalizations
- Access to the Medical Home
- Appropriate Treatment Receipt
- Satisfaction

Success Factors and Barriers

Potential Factors:
- Parent Portal:
  1. Work with Epic and MyChart
  2. Provide education
  3. Capture treatment preferences, current symptoms, and side effects
  4. Identify and track progress towards families' goals
  5. Provide decision support to the clinician and families
  6. Be sustainable and part of operations

Potential Challenges:
- Accessibility
- Involving new learning groups
- Parenting system issues: ensuring safety
- Integrating with workflow: ensuring information is used and not lost
- Familying shared family and clinical learn expectations

Patient Portal Results

Parent Interface

MyAsthma Portal Features

Clinician Interface

Preliminary Results

- Enrolled 39 users so far
- 77% have completed at least one monthly follow-up survey
- Family use of the portal has identified poor asthma control between office visits
- Through 12 monthly check-in surveys with 22 families: 4 uncontrolled asthma, 13 poorly controlled asthma, 1 medication side effects
- Results were automatically sent to the practices and prompted follow-up by MyChart message or phone call

Conclusion and Next Steps

- The MyAsthma Portal now supports safe, high-quality asthma care at CHOP
- This custom software, embedded in the EMR, provides a model for improving the quality and safety of care in various conditions and clinical settings.
- Future studies will adapt the system for ADHD portal
- The MyAsthma Portal is now implementing nationally as part of a study to explore the possibility of using health information technology to support shared decision making as part of the federal Meaningful Use Program.
Challenge

Children with autism have different reactions to medical procedures and other facets of healthcare. They require different approaches to ensure they are kept safe and that the care provided is the most effective.

For example, pain measurement systems that ask the patient to rank pain on a scale of 1-10 or choose from cartoon faces expressing more or less distress are not ideal for children with autism, who have difficulty reading facial expressions and who, when asked to choose a number between 1 and 10, might pick their favorite number.

With Chair’s Initiatives funding, a team at CHOP began to develop better tools and strategies for care for children with autism. They focused on the sedation unit, where children are given sedatives or tranquilizers before tests and procedures that require them to remain still, such as an MRI or spinal tap.

Accomplishments

• The team piloted a screening system to identify patients with autism or other developmental issues before their appointment. During scheduling, the parent is asked whether the child has developmental delays or special communication needs. The screening, which takes less than a minute, may be incorporated into scheduling Hospital-wide.

• The team created tools to help children and staff in the sedation unit, including a unit-specific screening system, tip sheets for staff, and social stories and “first-then” boards (preparation and coping tools that help children with autism).

• The team developed new recommendations for pain assessment for children with autism.

• The team created an interdisciplinary autism work group to share learning and strategies among units and specialties at CHOP.

• The team improved communication with parents. For example, the sedation unit’s website now has a “Children with Special Needs” section.

• The team improved staff training tools, including an “autism care” learning module on the “Learning-Link” employee training site.

• With other hospitals, the team began work on best practice guidelines for an autism-friendly hospital.
Improving Hospital Care and Service Delivery to Individuals with Autism Spectrum Disorders: A Pilot Program of Model Care Delivery within the Sedation Unit

Department of Pediatrics Chair’s Initiative
Eron Friedlander, MD MPH, Judith Miller, PhD, Jan Boswinkel, MD, Amy Kratchman, Susan Levy, MD

Project Aims

Needs Assessment (Phase 1):
1) Identify strategies used in completing medical interventions for children with Autism Spectrum Disorders safely and effectively.
2) Identify strengths and deficiencies in staff knowledge of interaction with and assessment of individuals with Autism Spectrum Disorders.
3) Identify hospital environmental factors that interfere with or facilitate care.

Pilot Program (Phase 2): Model Care Delivery within the Sedation Unit
To identify and pilot intervention strategies that will help improve quality of care for patients with autism in the sedation unit. (IV Placement RCT grew out of this aim)

Pain Assessment:
To describe how children with an Autism Spectrum Disorder understand and communicate about pain.

Outcomes

NEEDS ASSESSMENT: Key Concept: individualized care
1) Need improved capacity for productive provider-patient interactions, through better provider education, family preparation/empowerment and communication.
2) Need adaptive healthcare system with flexibility in patient flow and the physical environment.
3) Need for systematic identification of patients with autism to facilitate preparation and individualized care.

PILOT PROGRAM: Data at baseline indicated patient, family and staff safety were most prevalent concerns. Outcomes survey developed and piloted, will be administered in June, 2013.

PAIN ASSESSMENT: In describing pain, patients with autism prefer pointing, and cannot indicate severity on standard intensity scales.

IV PLACEMENT RCT: Patients tolerated IV placement better than expected by observation and parent report. (Preliminary data, collection not completed).

Barriers

No systematic way of identifying patients with autism prior to visit
Large staff, multiple shifts, present barriers to comprehensive training
Slow mail transit time for IV kits

Success Factors

Participation and support of Sedation unit leadership and Child Life
More detailed triage procedures
Super users identified and trained
Enthusiastic response from key personnel
Multiple training formats
Parents empowered to do their own preparations in advance

Accomplishments

Universal Screening, Behavioral Safety Issues: Piloted in Endocrine
Screened 438 patients at point of scheduling, 21% had developmental/behavioral diagnoses
Screening takes less than one minute (30%) and was easy for parents to answer (100%)
1. Is there a behavioral diagnosis or developmental delay that staff should be aware of? (17%)
2. Does your child have special communication needs? (5% = Yes)
3. Does your child sit still for a haircut, dental, or doctor’s exam? (5% = No)

Unit Specific Triage Procedure – Piloted in Sedation Unit
1. Is there a behavioral diagnosis or developmental delay that staff should be aware of?
2. Is your child verbal or non-verbal?
3. Does your child cooperate with taking oral medications?
4. Are there any specific triggers that upset your child in a medical environment?
5. Is there anything that calms your child in a medical environment or when he gets upset?

Intervention Tools Piloted in Sedation Unit
- Social Stories
- Visual Schedules
- First/Then Boards
- Tip Sheets
- Letters to Families
- Special Needs Info. on Website

Hospital Wide Implementation of Training and Intervention
- Learning Link for Autism Care – Summer 2013
- Autism Pathway – Fall 2013
- Interdisciplinary Autism Work Group established, coordination of parent and staff interventions & south & west, CHRU, ongoing roll out to other units

Partnerships with Other Hospitals
- Contacted other hospitals to join complementary projects

Next Steps and Sustainability
- EPIC work order for behavioral safety flag to identify patients.
- Approval and implementation of universal screening and unit specific triage procedures.
Challenge

Central lines are long-term IV lines that are used for a variety of purposes, including delivering medicines such as chemotherapy drugs and delivering nutrients for patients with compromised digestive tracts. Central line-associated bloodstream infections (CLABSI) cause many deaths and cost the healthcare system billions of dollars every year. Along with many hospitals, CHOP has made a concerted effort to reduce CLABSI rates in inpatients.

Some patients go home with central lines, and the care of the line is then in the hands of parents and home healthcare nurses. This Chair's Initiatives team, including an oncologist, surgeon, gastroenterologist, home healthcare administrator and others, decided to apply learning from inpatient CLABSI efforts to the outpatient setting, as well as define and address prevention challenges unique to outpatients.

Accomplishments

• The team’s efforts resulted in a 50 percent drop in outpatient CLABSI for all CHOP patients.
• The team developed an education and infection prevention kit for parents/caregivers.
• The team increased use of one CLABSI prevention tactic, ethanol locks, in patients with central lines for nutrients; this resulted in a dramatic decrease in infections for that group.
• The team established relationships with home healthcare organizations to facilitate training in CLABSI prevention techniques for CHOP patients at home.
• The team began collecting data about outpatient CLABSI; a comparison between outpatient and inpatient rates showed they correlate closely.
• The team created the permanent position of nurse coordinator for outpatient CLABSI.

Team

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Millie Boettcher, M.S.N., C.R.N.P.  Mark Magnusson, M.D., Ph.D.
Susan Coffin, M.D., M.P.H.  Maria Mascarenhas, M.D.
Preventing Outpatient CLABSI
A Department of Pediatrics Chair’s Initiative

Project Goal
To reduce the incidence of central line-associated bloodstream infections in the outpatient/homecare setting through education, implementation of evidence-based practices, and data tracking and enhanced communication.

Accomplishments
1) Reduced outpatient CLABSI numbers for all CHOP patients by over 50%.
2) Instituted bedside reviews for CLABSI acquired in outpatient settings. Data collected for 85 reviews as of January 2014.
3) Instituted and increased use of ethanol locks for high risk patients at risk for CLABSI; 90% decrease in outpatient CLABSI for patients on home TPN as part of the Intestinal Rehabilitation Program.
4) Reduced outpatient CLABSI in Oncology patients by 22% from 2012-2013.
5) Created a permanent position of nurse coordinator for outpatient CLABSI to ensure ongoing work and data collection in this area.

Performance Measures

- CHOP Outpatient CLABSI numbers reduced by over half.

Performance Measures, cont.

Oncology Outpatient CLABSI rates reduced by 22%:

<table>
<thead>
<tr>
<th>Year</th>
<th>CLABSI Rate/1000 Patient Line Days</th>
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<tbody>
<tr>
<td>2012</td>
<td>0.46</td>
</tr>
<tr>
<td>2013</td>
<td>0.36</td>
</tr>
</tbody>
</table>

Addition of use of ethanol lock prophylaxis in high risk patients on home TPN reduced CLABSI by 90% in the short term:

Pre-lock CLABSI rate
0.23 CLABSI/patient mo = 2.8 CLABSI/pt yr

Post-lock CLABSI rate
0.021 CLABSI/patient mo = 0.26 CLABSI/pt yr

Conclusions
Reinforcement of established central line care practices, education, and judicious use of ethanol lock prophylaxis have reduced CLABSI in the outpatient settings at CHOP.

Future Directions
Ethanol lock trials are ongoing in selected inpatient and additional outpatient settings.

Other Outpatient CLABSI team will use ongoing data collection and analysis to identify new opportunities to further reduce outpatient CLABSI.

Updated March 2014
Challenge

The time when a young adult must transition from pediatric to adult healthcare can be difficult. Some have trouble finding an adult doctor, and their care may lag and their health suffer. There have been numerous efforts at CHOP to improve the transition from pediatric to adult specialists, such as gastroenterologists.

Finding a good adult primary care provider is as important as finding specialists, especially for patients with chronic conditions. A Chair’s Initiatives team decided to analyze the needs of young adult patients with chronic conditions in CHOP-affiliated primary care practices, and then create tools to help them successfully transition to adult primary care.

Accomplishments

- The team used CHOP data to identify more than 400 patients, 19 years or older, with chronic conditions at CHOP primary care practices and enrolled 32 in a randomized controlled pilot feasibility study.
- The team identified important clinical and demographic information about the patients, such as insurance type, complexity of illness, and whether an intellectual disability or behavioral health disorder exists.
- The team provided study patients with varying levels of transition support including a transition consult and/or a transition “Carebinder,” and continues to collect and analyze data to determine whether the interventions have improved transition to adult care and patient and provider satisfaction with the transition experience.
- The team surveyed over 300 primary care doctors and nurses and medical and surgical specialists about transition expectations and identified major barriers to transition including lack of personnel to deliver services; limited time; parental reluctance; and patient attitudes.
- The team identified adult primary care providers willing to care for patients with chronic conditions.
- The team established a young adult transition-focused clinic within a larger University of Pennsylvania internal medicine practice and launched the Adult Care at CHOP Program, a clinical consult program for young adults (ages 24 years and older) admitted to CHOP.
- The team developed materials to help with transition for both patients and providers, including updating the www.chop.edu/transition website, developing a community transition resource list and adult provider list for patients, and creating a “transition summary” for pediatric providers to fill out in CHOP’s electronic medical record system.
- The CHOP Division of Social Work is offering part-time salary support for the continuation of transition initiatives.

Team

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Symme Trachtenberg, M.S.W., L.S.W.
Elyse Salek
Nadavya Stollon
Elizabeth Wallis, M.D.
Lisa Schwartz, Ph.D.
Caren Steinway
Transitioning from Pediatric to Adult Services: A Primary Care Based Model

Project Goal, Aims and Methods

Goal: To improve transition for patients ≥19 years with chronic conditions in CHOP Primary Care practices.

Aim 1: To improve transition-related and self-care skills in patients.

Aim 2: To improve transition-related satisfaction for patients, families and providers.

Aim 3: To improve successful transition to adult providers.

Methods:
1. Pilot feasibility study in CHOP Primary Care Network evaluating multiple transition interventions.
2. Disseminate Provider survey to understand current transition practices at CHOP.
3. Develop transition-related materials, resources and services for improving care and future dissemination.

Performance Measures

PILOT STUDY: Baseline Summary

Demographic & Clinical Characteristics (N=144)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>n</th>
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<tbody>
<tr>
<td>Gender Male</td>
<td>13 (2)</td>
<td>60</td>
<td>27</td>
</tr>
<tr>
<td>Female</td>
<td>18 (6)</td>
<td>50</td>
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</tr>
<tr>
<td>Age</td>
<td>2.6 (2.5)</td>
<td>2</td>
<td>21</td>
</tr>
<tr>
<td>Know what health insurance covers?</td>
<td>2.6 (2.5)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Tell doctor about changes in health?</td>
<td>4.2 (2.6)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Test Self-Advisory (summary domain score)</td>
<td>4.5 (2.3)</td>
<td>21</td>
<td></td>
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<tr>
<td>Fill out medical record forms?</td>
<td>4.5 (2.3)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Make list of questions before doctor’s visits?</td>
<td>3.2 (2.1)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Request accommodations &amp; support you need?</td>
<td>3.1 (2.0)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Parent Self-Management Overall (summary score)</td>
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<td>21</td>
<td></td>
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<tr>
<td>Parent Self-Advocacy (summary score)</td>
<td>1.9 (1.0)</td>
<td>21</td>
<td></td>
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*Mean = four global stratification domains & disease management utility

Provider Survey: Transition-Self Care Expectations of Pediatric Providers

Question Yes (%) | No (%) | Sometimes (%) | Mean Score |
<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Age ask pts about medications?</td>
<td>72 (71)</td>
<td>21 (22)</td>
<td>9.2 (9.0)</td>
</tr>
<tr>
<td>Age ask pts about medical history?</td>
<td>72 (71)</td>
<td>21 (22)</td>
<td>9.2 (9.0)</td>
</tr>
<tr>
<td>Age ask pts about transitions?</td>
<td>72 (71)</td>
<td>21 (22)</td>
<td>9.2 (9.0)</td>
</tr>
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<td>21 (22)</td>
<td>9.2 (9.0)</td>
</tr>
</tbody>
</table>

PROVIDER SURVEY: Transition Summary

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender Male</td>
<td>13 (2)</td>
<td>60</td>
<td>27</td>
</tr>
<tr>
<td>Female</td>
<td>18 (6)</td>
<td>50</td>
<td>21</td>
</tr>
<tr>
<td>Age</td>
<td>2.6 (2.5)</td>
<td>2</td>
<td>21</td>
</tr>
<tr>
<td>Know what health insurance covers?</td>
<td>2.6 (2.5)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Tell doctor about changes in health?</td>
<td>4.2 (2.6)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Test Self-Advisory (summary domain score)</td>
<td>4.5 (2.3)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Fill out medical record forms?</td>
<td>4.5 (2.3)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Make list of questions before doctor’s visits?</td>
<td>3.2 (2.1)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Request accommodations &amp; support you need?</td>
<td>3.1 (2.0)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Parent Self-Management Overall (summary score)</td>
<td>2.0 (2.0)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Parent Self-Advocacy (summary score)</td>
<td>1.9 (1.0)</td>
<td>21</td>
<td></td>
</tr>
</tbody>
</table>

*Mean = average score for all transition questions

Additional Accomplishments:
- Developed transition materials with Community Resource List, Adult Provider List, REACH for independence group curriculum & manual, www.chop.edu/transition website, CHOP transition team, and CHOP transition website.
- Developed transition trauma consultation program with state and national transition organizations.
- Implemented additional REACH groups (e.g., REACH for Epilepsy).
- Surveyed over 300 primary care doctors and nurses and medical and surgical specialists about transition expectations.

Next Steps
- Continue to collect and analyze data to determine whether the interventions have improved transition to adult care and patient and provider satisfaction with the transition experience.
- Continue the REACH and Care and Collaborate programs, website updates and the Transition Special Interest Group activities.
- Continue partnership with MyChart and EPIC to make transition resources more accessible for providers.
- Continue to analyze data on provider survey results, patient reported outcomes and post-treatment health care utilization.

Barriers or Success Factors

- Recruitment and engagement of young adult population difficult.
- Need to help patients internalize healthcare as a top priority sooner (e.g., earlier transition preparation).
- Data reveal that primary care physicians are more readily doing this than specialists/surgeons.
- Consider offering ecologically and developmentally sensitive interventions via technology and/or at already scheduled appointments.
- Barriers to transition:
  - Insufficient knowledge of the transition process.
  - Insufficient knowledge of the transition process.
  - Insufficient knowledge of the transition process.
  - Insufficient knowledge of the transition process.

*Adjusted for gender, race, education, and marital status per week.
A Shared Decision-making Portal for Pediatric Chronic Illness

**Presentations**
Fiks AG, Grundmeier RW, Practice-Based Research Using the Electronic Health Record, invited lecture, Informatics Grand Rounds, The Johns Hopkins University School of Medicine, Baltimore, Md.

**Grants**
$500,000 grant from AHRQ (R18 HS022689-01) to study the feasibility of using portals to satisfy meaningful use requirements. We will adapt the portal content and include 10 practices from around the country (part of the American Academy of Pediatrics’ PROS Network) as well as 10 CHOP practices.

**Publications**

Improving Hospital Care for and Service Delivery to Individuals with Autism Spectrum Disorders

**Presentations**
Davignon M, Care for Children with Autism Spectrum Disorders in the Hospital, Department of Physical Disabilities and Rehabilitation Lecture Series, CHOP, May 2012.
Friedlaender E, Hospital Care for Children with Autism Spectrum Disorders, Department of Child and Adolescent Psychiatry and Behavioral Science Quarterly Meeting, CHOP, March 2013.
Friedlaender E, Fein J, Behavioral Health Care in the Pediatric Emergency Department, Emergency Department Nursing Grand Rounds, CHOP, April 2013.
Friedlaender E, Hospital Care for Children with Autism Spectrum Disorders, RN MD Grand Rounds, CHOP, April 2013.
Friedlaender E, Davignon M, Gabrielsen T, Miller J, Improving Hospital-Based Services and Care to Individuals with Autism Spectrum Disorder (ASD), submitted as workshop for Pediatric Academic Societies Meeting, Vancouver, May 2014.

**Grants**
Friedlaender E, Ely E, Pain Assessment in Children with Autism Spectrum Disorders, Mayday Fund, $30,000.

**Publications**

**Abstracts**
Minds Matter: Improving Pediatric Concussion Management

Presentations
From 2011-2013 members of the Minds Matter team completed more than 60 presentations, with audiences including parents, principals, teachers, coaches, school nurses, trauma surgeons, nursing students, primary care pediatricians and nurse practitioners, community hospitals, neurosurgeons, Congress, emergency room staff, and many others. Here are a few of the presentations:


Arbogast KB, McGinley AD, Master CL, Grady MF, Zonfrillo MR, Primary Care Emphasis on School-Based Recommendations for Pediatric Concussion Management, Pediatric Academic Societies Annual Meeting, Boston, MA, April-May 2012.

Zonfrillo M, Pediatric Concussion, Emergency Medicine Residency Grand Rounds, York Hospital, York, PA, March 2012.


Grady M, Concussion: Pathophysiology and Implications for Return to School, 11th Annual Disabilities Conference, University of Scranton.


Media:
Members of the Minds Matter team have contributed to or been featured in more than 70 media stories about concussion all over the United States and the world, including CNN, The Philadelphia Tribune, WTIT, Boston Herald, U.S. News & World Report, Toronto Telegraph, The Baltimore Sun, The Denver Post, Chicago Tribune, Fox News, Reuters and many other media outlets.

Transitions from Pediatric to Adult Services: A Primary-care-based Model

Presentations


Publications


Pediatric Annals Special Issue on Concussion (Guest Editors)


# The Chair’s Initiatives

## Past

### Round 1 (2006–2008)

<table>
<thead>
<tr>
<th>Access Nurse Advisor and Care Coordination</th>
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<tbody>
<tr>
<td>Developing nursing roles, systems and tools to support patients, families and providers in coordinating both access and care</td>
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<table>
<thead>
<tr>
<th>ADHD in Primary Care</th>
</tr>
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<tbody>
<tr>
<td>Creating computer tools, conferences and other supports to help primary care pediatricians learn and manage patients with attention deficit hyperactivity disorder</td>
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<table>
<thead>
<tr>
<th>Automated Appointment Reminders</th>
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<tr>
<td>Implementing a computerized system to place standardized reminder calls across specialties to support continuity of care</td>
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<tr>
<th>Center for Bone Health</th>
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<tr>
<td>Providing specialized care for children with poor bone health and helping establish international care guidelines</td>
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<table>
<thead>
<tr>
<th>Center for Pediatric Eosinophilic Disorders</th>
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<tbody>
<tr>
<td>Providing specialized care for rare allergic disorders</td>
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<table>
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<th>Database Development</th>
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<tbody>
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<td>Developing databases and web-based applications to support physicians in research and care</td>
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<th>Multidisciplinary Cancer Survivorship Program</th>
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<tbody>
<tr>
<td>Creating a monthly clinic where cancer survivors see numerous specialists with expertise in the late effects of cancer treatment</td>
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<tr>
<th>Office of Fellowship Programs</th>
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<tbody>
<tr>
<td>Coordinating and streamlining application, evaluation, curriculum development and accreditation for all fellowship programs in Pediatrics</td>
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<thead>
<tr>
<th>Pediatric Knowledgebase</th>
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<tr>
<td>Creating a web-based application that combines data about drugs with data about individual patients to help improve outcomes</td>
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<tr>
<th>Sudden Cardiac Death Prevention</th>
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<tr>
<td>Providing screenings for undiagnosed heart irregularities in children and teens, and training in CPR and automated external defibrillators for schools</td>
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## Round 2 (2008-2010)

<table>
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<tr>
<th>Anticoagulant Management Program</th>
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<tr>
<td>Improving monitoring and care for children taking “blood thinners”</td>
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<tr>
<th>Chemotherapy Tracking Project</th>
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<tr>
<td>Computerizing records of cancer patients’ complex drug regimens</td>
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<table>
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<tr>
<th>CHOPLink Implementation, Quality and Patient Safety</th>
</tr>
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<tbody>
<tr>
<td>Linking clinicians with computer specialists to ensure technology improves care</td>
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<tr>
<th>Collaborative Clinical Pathways</th>
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<tbody>
<tr>
<td>Establishing a framework so that computerized care guidelines widely used by residents and other physicians can be created more easily</td>
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<tr>
<th>Intestinal Rehabilitation Program</th>
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<tr>
<td>Coordinating and improving care for children with severe conditions that cause intestinal failure</td>
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<tr>
<th>Unit-based Patient Safety Walk-rounds</th>
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<tr>
<td>Providing a forum for the safety concerns of families and staff</td>
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## Future


<table>
<thead>
<tr>
<th>COMEDO for Acne</th>
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<tbody>
<tr>
<td>Developing an app doctors can use in assessing and treating acne patients</td>
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<table>
<thead>
<tr>
<th>Recognizing and Addressing Peer Bullying</th>
</tr>
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<tbody>
<tr>
<td>Designing tools to help primary care pediatricians and other providers identify bullying and respond effectively</td>
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<tr>
<th>Identification, Remediation and Prevention of Chronic Glucocorticoid Therapy Effects</th>
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<tbody>
<tr>
<td>Developing standards to identify, monitor, remediate and prevent the serious side effects of chronic steroid use</td>
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<table>
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<tr>
<th>Thrombosis Prevention and Treatment in Cardiac Patients</th>
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<tbody>
<tr>
<td>Developing strategies to reduce the incidence and complications of blood clots in cardiac patients</td>
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<tr>
<th>Text Messaging Interventions</th>
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<tbody>
<tr>
<td>Studying the effectiveness of texting in improving knowledge and health promotion for adolescents and young adults completing treatment for cancer</td>
</tr>
</tbody>
</table>
The Chair’s Initiatives is an internal grant program at The Children’s Hospital of Philadelphia. It funds physicians, nurses, computer specialists and others who focus their knowledge and team-building skills on areas for improvement at CHOP.

The program represents an excellent opportunity for donors interested in helping incredibly bright, motivated teams quickly bring about change that benefits patients and families. For more information call 267-426-5332 or visit GiftOfChildhood.org.