Children’s Hospitals Neonatal Database: Promoting Quality in Neonatal/Infant Surgical Care

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Background of the Children’s Hospitals Neonatal Consortium (CHNC) and The Childrens Hospitals Neonatal Database (CHND)

CHNC is a grassroots organization of NICU leaders in children’s hospitals, formed in 2006

CHNC partnered with The Child Health Corporation of America (now the Children’s Hospitals Association) to develop the Children’s Hospitals Neonatal Database (CHND), launched in 2010
Why Another NICU Database?

Most NICU’s:
• Large cohorts with common neonatal disease
• Common complications (NEC, BPD etc) can be used for quality measures
• Large body of data already exists on these patients and benchmarking has been associated with marked improvements in their care

Regional NICU Patients are Different:
• Multiple small cohorts with uncommon disease
• Common complications often preexisting on admission
• Medically complex, often have surgery
• Not much data; historically few benchmarks
### CHND: Improve care for infants in tertiary NICU’s

**CHNC Forms**
- 2006 Grassroots Consortium
- Started with 7, grew to 17 sites who were founding members in 2007
- 12/06-12/08: 16 inperson meetings

**Partnership and DB Development**
- RFP
- 2008 CHNC-CHCA partnership
- Consensus on data fields and definitions
- Database design development
- MOP Development

**Deployment**
- 2010 data entry begins
- Ongoing development
- 2011 reports launched
- Statistician hired
- CLABSI Collaborative begins

**Initial results**
- Collaborative analytics benchmarking
- Periop Collaborative begins
- Site-to site comparative reports
- Focus groups established
- Publications begin
- Potentially better practices

**2015**
- 15 publications
- 29 sites
- Periop Collaborative near completion
- TEF Module development
- Beginning development of CHND 2.0

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>Grassroots Consortium started</td>
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<tr>
<td>2007</td>
<td>16 inperson meetings</td>
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<tr>
<td>2008</td>
<td>CHNC-CHCA partnership established</td>
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<tr>
<td>2009</td>
<td>Consensus on data fields and definitions</td>
</tr>
<tr>
<td>2010</td>
<td>Data entry begins</td>
</tr>
<tr>
<td>2011</td>
<td>Reports launched</td>
</tr>
</tbody>
</table>

**Start-up** | **Growth**

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Children’s Hospital Neonatal Database: Participation 2015

1. Alfred I. duPont Hospital for Children, Wilmington
2. All Children’s Hospital Johns Hopkins Medicine, St. Petersburg
3. Ann & Robert H. Lurie Children’s Hospital of Chicago
4. Arkansas Children’s Hospital, Little Rock
5. Boston Children’s Hospital
6. Children’s Healthcare of Atlanta at Egleston
7. Children’s Healthcare of Atlanta at Scottish Rite
8. Children’s Hospital and Medical Center, Omaha
9. Children’s Hospital Colorado, Denver
10. Children’s Hospital of Pittsburgh of UPMC
11. Children’s Hospital of Wisconsin, Milwaukee
12. Children’s Medical Center Dallas
13. Children’s Mercy Hospitals and Clinics, Kansas City
14. Children’s National Medical Center, Washington, DC
15. Children’s of Alabama*
16. Children’s Hospital Los Angeles
17. Children’s Hospital of Michigan, Detroit
18. Cook Children’s Medical Center, Fort Worth
19. Florida Hospital for Children, Orlando
20. Hospital for Sick Children, Toronto, CANADA
21. Le Bonheur Children’s Hospital, Memphis
22. Nationwide Children’s Hospital, Columbus
23. Primary Children’s Hospital, Salt Lake City
24. Rady Children’s Hospital San Diego
25. Seattle Children’s
26. St. Louis Children’s Hospital
27. Texas Children’s Hospital, Houston
28. The Children’s Hospital of Philadelphia
29. UCSF Benioff Children’s Hospital Oakland

2 Additional New Sites expected last qtr 2015
- Children’s Hospital of Orange County
- American Family Children’s Hospital, Madison

All admitted infants ~EOC 20,000/yr
The CHND Database Structure

Web Collection Tool
Core data on all admissions

GI anomalies
Periop Data
TEF
CDH
HIE
NEC
BPD

Manual and automated options, latter WIP

PHIS
PACT

Other repositories as needed
Manual and automated options

Hospital compared To aggregate for local use
Comparative to drive CHNC improvement priorities

Peer groupings from site profile

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What have we found?

SPECIAL FEATURE
The Children’s Hospitals Neonatal Database: an overview of patient complexity, outcomes and variation in care

K Murthy¹, FD Dykes², MA Padula³, EK Pallotto⁴, KM Reber⁵, DJ Durand⁶, BL Short⁷, JM Asselin⁸, I Zaniletti⁹ and JR Evans³

The Children’s Hospitals Neonatal Consortium is a multicenter collaboration of leaders from 27 regional neonatal intensive care units (NICUs) who partnered with the Children’s Hospital Association to develop the Children’s Hospitals Neonatal Database (CHND), launched in 2010. The purpose of this report is to provide a first summary of the population of infants cared for in these NICUs, including representative diagnoses and short-term outcomes, as well as to characterize the participating NICUs and institutions. During the first 2½ years of data collection, 40,910 infants were eligible. Few were born inside these hospitals (2.8%) and the median gestational age at birth was 36 weeks. Surgical intervention (32%) was common; however, mortality (5.6%) was infrequent. Initial queries into diagnosis-specific inter-center variation in care practices and short-term outcomes, including length of stay, showed striking differences. The CHND provides a contemporary, national benchmark of short-term outcomes for infants with uncommon neonatal illnesses. The data will be valuable in counseling families and for conducting observational studies, clinical trials and collaborative quality improvement initiatives.

*Journal of Perinatology* advance online publication, 6 March 2014; doi:10.1038/jp.2014.26

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### CHND Overall

**June 2010 –October 2015**

<table>
<thead>
<tr>
<th>Metric</th>
<th>Value</th>
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<tbody>
<tr>
<td>n of NICU sites entering data</td>
<td>29</td>
</tr>
<tr>
<td>n of NICU admissions (episodes of care, EOC)</td>
<td>100K</td>
</tr>
<tr>
<td>n of patient NICU days (closed EOC only)</td>
<td>&gt; 2 million</td>
</tr>
<tr>
<td>n of surgical time frames (closed EOC only)</td>
<td>&gt;45K</td>
</tr>
<tr>
<td>N of surgical procedures</td>
<td>&gt;63K</td>
</tr>
</tbody>
</table>

Source: CHND, July 2015
CHND Surgical Population

24% admitted primarily for surgical indications
31% of all CHND NICU admissions involve 1 or more surgical time frames

Over 50% of infants undergoing surgery have 2 or more procedures

Source: CHND: 7.2015 snapshot
Many of the CHND “uncommon” diseases are surgical

<table>
<thead>
<tr>
<th>Disease</th>
<th>Count</th>
</tr>
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<tbody>
<tr>
<td>CPAM</td>
<td>459</td>
</tr>
<tr>
<td>sCLD (Spec Dx Trigger)</td>
<td>510</td>
</tr>
<tr>
<td>Short Gut Syndrome</td>
<td>513</td>
</tr>
<tr>
<td>Chylothorax</td>
<td>577</td>
</tr>
<tr>
<td>Omphalocele</td>
<td>658</td>
</tr>
<tr>
<td>Duodenal atresia</td>
<td>838</td>
</tr>
<tr>
<td>Jejunal + ileal atresia</td>
<td>914</td>
</tr>
<tr>
<td>Myelomeningocele</td>
<td>1179</td>
</tr>
<tr>
<td>CDH</td>
<td>1195</td>
</tr>
<tr>
<td>Imperforate anus</td>
<td>1265</td>
</tr>
<tr>
<td>NEC, surgical</td>
<td>1612</td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>1621</td>
</tr>
<tr>
<td>Intestinal Perforation</td>
<td>1745</td>
</tr>
<tr>
<td>Gastrochisis</td>
<td>1837</td>
</tr>
<tr>
<td>HIE</td>
<td>2586</td>
</tr>
<tr>
<td>sBPD - (Spec Dx Trigger)</td>
<td>3040</td>
</tr>
</tbody>
</table>

Source: CHND July 2015 Snapshot
Quaternary population: High volumes of surgeries

- PDA Ligation: 2311
- Fundoplication: 1887
- Ostomy takedown (small or large bowel): 1554
- Ileostomy: 1514
- Gastroschisis - Primary Repair: 1389
- Tracheostomy: 1380
- Colostomy: 1127
- Duodenal Atresia/Stenosis/Web Repair: 718
- Large bowel resection (colectomy): 644
- Jejunostomy: 471
- Omphalocele - Primary Repair: 372

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Huge *site to site* variation in care of surgical patients, wherever we look.

Percent of patients by site with post op temp less than 36°C

Percent gastroschisis patients home with feeding tube by site
How do we determine best outcomes and achieve them?

Varied outcomes, independent of BSI, late preterm, gender, year, NEC, type of closure, repaired in NICU, duration of empiric ABX and TPN days

Gastroschisis LOS<50d/no tube feedings at D/C

71.7% = overall prevalence of outcome

Centers' better clinical outcomes

P<0.01 for center
How do we determine and provide high value care?

Gastroschisis outcome plotted against hospital costs

% of infants LOS<50 days and nipping at D/C

Adjusted RCC costs ($)
Developing a systematic process to begin to understand our complex, high risk patient population

Create the baseline knowledge from which to improve disease specific care as well as unit level care

Areas of Focus

Overview

CIQI

sCLD

Gastrochisis

CDH

HIE

NEC

Mortality

Descriptive paper

CLABSI 2 papers

Descriptive (surgical burdens)

Descriptive (Nutrition)

Descriptive Interventions

Outcomes

Outcome prediction

Resource utilization & inter-center variations

Descriptive & comparative effectiveness

Predictions paper

Outcomes paper

Descriptive paper

Comparative Effectiveness

Resource utilization & inter-center variations

Resource utilization & inter-center variations

Resource utilization & inter-center variations

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Travelling the path from data to improvement

Data → Analysis → Evidence → Translation → Best Practice Standards → Implementation → Reduce Cost & Improve Outcomes

- CDH
- NEC
- Gastrochisis
- HIE
- BPD

- Overview
  - Journal of Perinatology
  - Mar 2014
  - The Children’s Hospital Neonatal Database: An Overview of Patient Complexity, Outcomes and Variation in Care

- CIQI
  - Journal of Perinatology
  - Apr 2015
  - Short-Term Outcomes After Perinatal Hypoxic-Ischemic Encephalopathy

- BPD
  - Journal of Perinatology
  - Jan 2014
  - Predicting Death or Tracheostomy in Infants with Severe Bronchopulmonary Dysplasia

- HIE
  - Journal of Perinatology
  - Apr 2014
  - Short-Term Outcomes and Medical and Surgical Interventions in CDH

- NEC
  - Journal of Perinatology
  - Oct 2014
  - High Surgical Burdens for Infants with Severe Chronic Lung Disease

- CLD
  - American Journal of Perinatology
  - May 2013
  - Postnatal Weight Gain in Preterm Infants with Severe BPD

- Gastrochisis
  - Pediatrics
  - In press
  - SLUG BUG: Quality Improvement with Orchestrated Testing leads to NICU CLABSI reduction

- CIQI
  - Am J of Medical Quality
  - In press
  - Orchestrated Testing: Innovative Approach to a Multicenter Improvement Collaborative

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Philosophy: align/collaborate with other NICU care stakeholders
Contributing to USNWR Best Children’s Hospital Survey

CHND participation and measures included as scoring criteria in the 2014-2015 NICU surveys

Based on CHND target benchmark data, two new objective patient-specific metrics added to the Neonatology Survey

- Rate of breast-milk usage
- First post-operative temperature (in NICU)

Collaborate with USNWR for other metrics in 2015-2016

Explored additional disease specific LOS and mortality targets

Goal of Disease-specific, risk-adjusted outcomes
Making headway in IMPROVING Level IV NICU care
#1 CIQI Project: CLABSI Reduction: “Slug Bug”

• Reduction of CLABSI by 38.7% : from 1.39/1000 to 0.85/1000 line days*
• Estimated cost saving $1.6 million
• Orchestrated testing of bundled care data
• Identified generalizable clinical practices that improve outcome

Making Headway in IMPROVING Level IV NICU Care: #2 CIQI Project: “STEPP IN”

“Safe Transitions and Euthermia in the Peri-operative Period in Infants and Neonates” Rationale:

• 1/3 of all CHND patients experience periop care
• The surgical neonate often has complex disease
• The perioperative time period is very high risk
  – Operative procedure, anesthesia
  – Multiple disciplines involved
  – Multiple handoffs, ? Quality of communication
  – Often requires transport
• Large variations known to be present
• Interdisciplinary work needed for this project might spread beyond the project
1. Perioperative Handoff

*Reduce care failures* by 30% and *implement a standardized communication process* for postoperative handoff for over 90% of transfers of care for NICU patients undergoing surgery by December 2014 and sustain over 12 months.

2. Postop euthermia

*Decrease the incidence of hypothermia* (≤36°C) by 50%, as measured on the first temperature within 30 minutes of return to NICU, by December 2014 and sustain over 12 months.
STEPP IN Results: Lowering Post-Operative Hypothermia
STEPP IN Handoff Communication Care Failures

Respiratory Handoff Care Failures

Data as of 9/16/15
Successes in Perioperative CIQI Project

1. Collaborated across centers and among disciplines
2. Standardized processes for communication
3. Ensured that providers received accurate and complete information as measured by
   • Communication failures decreased by 57%
   • Respiratory communication failures decreased by 64%
4. Improved care
   • Postop hypothermia decreased by 48%
CHND Planning

- CIQI: Continue the Periop care work, develop 3rd CIQI Project
- A number of special diagnosis manuscripts in progress
- Improvements of current database and planning for “CHND 2.0”
  - Opportunities for redesign of existing modules
  - Opportunities to collaborate during development to achieve better alignment with important stakeholders in NICU care
  - TEF “Special Module” - development complete, roll out 2016

Seeking surgical input on data fields and definitions and collaboration in CIQI and research projects
TEF Module Development

- Participants 2013 + 2015
  - Lauren Berman, Surgery Wilmington
  - Bev Brozanski, Neo, Pittsburgh
  - Matt Clifton, Surgery, Atlanta
  - Ankur Datta, Neo, Milwaukee
  - Cassidy Delaney, Neo, Pittsburgh
  - Jackie Evans, Neo, Phila
  - Holly Hedrick, Surgery Phila
  - Karna Murthy, Neo, Chicago
  - Girija Natarajan, Neo Detroit
  - Mike Padula, Neo, Phila
  - Shawn St Peter, Surgery, Kansas City
  - Greg Sysyn, Neo, Atlanta
  - Dan Swarr, Genetics, Neo, Phila
CHND Goals around Neonatal Surgical Disease:

Collaborate to:

• Develop a prioritization framework for quality improvement and comparative effectiveness research
• Establish condition-specific meaningful quality metrics
• When possible, merge or share data between neonatal-surgical datasets
• Align data fields and definitions; work can be complementary (NSQIP, VON, NICHD, CDH databases)
CHNC Philosophy around Neonatal Surgical Disease……

- Can’t afford to duplicate efforts
- Don’t want to compete
- Surgery and neonatology need to work together on a national level to optimally improve knowledge and care for surgical infants
- We’re all busy: need a framework to move this forward
Opportunity to transform care for our patients

- Silos
- “Expert “
- Authority
- Control
- Self interest

→ Collaboration
→ Evidence
→ Measurement
→ Transparency
→ Public interest
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Jeanette Asselin, Oakland
Kris Reber, Columbus
Francine Dykes, Atlanta
Michael Padula, Philadelphia
Jean Pallotto, Kansas City
Billie Short, Washington DC

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Rick McLead, Columbus
Susan Moran, Denver
Lorna Morelli, CHA
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Joan Smith, St Louis

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Margaret Holston, Columbus
Rick McLead, Columbus
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Anthony Piazza, Atlanta
Rakesh Rao, St Louis
Natalie Rintoul, Philadelphia
Doreen Soliman, Joan Smith, St Louis

Many others

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www.TECHNC.org