History and Infrastructure of the Pediatric Emergency Care Applied Research Network (PECARN)

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Disclosures

• Funding

  Emergency Medical Services for Children Network for the sustainability of a Pediatric Emergency Care Applied Research Network. U03MC0007-11, Maternal Child Health Bureau

• No conflicts of interest
Objectives

1. Describe the infrastructure used to support the PECARN network and research studies

2. Identify challenges to conduct or large scale, multicenter prospective research in pediatric emergency medicine (PEM)

3. Describe the power and complexities of the PECARN Registry for large data research
What is PECARN?

• First federally-funded pediatric emergency medicine (PEM) research network in the US

• **Goal**: Conduct meaningful and rigorous multi-institutional research into the prevention and management of acute illnesses and injuries in children and youth across the continuum of EM health care

• Particularly useful to conduct studies in need of large sample sizes to analyze relatively rare outcomes
Why did we form PECARN?

• Prior multicenter network: Pediatric Emergency Medicine Collaborative Research Committee (1994)
  • Largely retrospective studies
  • No funding required
  • Open to many institutions

• Limitations
  • Fully dependent on volunteerism
  • Onerous regulatory management
  • No organized method for data management and analysis
  • Data issues: inadequate sample, case ascertainment, missingness
PECARN

• Federally-funded since 2001
  • HRSA/Maternal Child Health Bureau
  • Emergency Medical Services for Children (EMSC) program
  • Funds support infrastructure, **NOT** projects

• Infrastructure Composition (2001)
  • 6 Research Nodes: Pediatric and general EDs
  • Data Coordinating Center
  • Competitive renewal every 4 years

Current PECARN Organization

- 6 Research Node Centers
  - 18 hospital EDs
  - 6 Emergency Medical Service Affiliate agencies (1/node)

- 1 Prehospital node (3 EMS agencies)

- Data Coordinating Center (DCC, Univ of Utah)
PECARN: 2021

- Data Coordinating Center
- GLEMSCRN Node
- HOMERUN Node
- PEM-NEWS Node
- PRIME Node
- SPARC Node
- WPEMR Node
- CHaMP Node
- EMS Affiliate Sites
PECARN Node Example

• Pediatric EM Northeast, West, and South (PEM-NEWS)
  • Columbia/Morgan Stanley: Maria Kwok (Site PI)
  • Texas Children’s Hospital: Andrea Cruz (Site PI)
  • Children’s Hospital Colorado: Rakesh Mistry (Site PI)
  • Aurora Fire EMS Affiliate: Katheen Adelgais (EMSA PI)

• PEM-NEWS Nodal Administration
  • Peter Dayan (Primary Investigator)
  • Raquel Shrager (Nodal administrator)
PECARN Enrollment

• Prospective enrollment at each ED
  • Research Coordinator (1.0 FTE funded)
  • Additional RC or PRAs (Funded by each study)

• Data Coordinating Center
  • Centrally created IRB, consent, and data collection forms
  • Data management (OpenClinica and QueryManager)
  • Statistical analysis
DCC Faculty and Staff

• DCC PI: PECARN leadership and governance
• Project management (20)
• Data management/informatics (13)
• Biostatistics support (6 PhD/15 MS)
• IT systems (12)
• Manuscript development
• Concept-to-grant development process
Submission of PECARN Studies

• Most originate within the existing EDs and EMSAs

• Non-PECARN investigators can submit with sponsorship from existing PECARN node

• Benefits
  • Access to over 1,000,000 ED visits per year
  • Scientific expertise
  • Data management and analysis via DCC
  • High extramural funding rate
Submission Process/Timelines
Submission Process/Timelines
Submission Process/Timelines

• Development within Node and Nodal Approval
• Concept submission/presentation to PECARN SC
  • Vote for acceptance
  • Feedback provided
• Protocol/Grant Submission
  • Subcommittee feedback
  • No vote
• Protocol/Grant Submission (for vote)
• PECARN Approval...*then* submit to funding agency
2001-Pres: Concepts, Protocols, Grants

Funding rate: 75%

- Concept Submitted: 138
- Concept Approval: 106
- Protocol Approved: 84
- Grant Submitted: 65
- Externally Funded: 48
- Internally funded: 12

Protocols, Concepts Grants
PECARN Annual Funding

Infrastructure funding

Total External funding


$0 $2,000,000 $4,000,000 $6,000,000 $8,000,000 $10,000,000 $12,000,000

$0 $2,000,000 $4,000,000 $6,000,000 $8,000,000 $10,000,000 $12,000,000


Infrastructure funding

Total External funding
Foci of PECARN Research

Disease Processes
• Traumatic injuries
• Respiratory illnesses
• Infectious diseases
• Sickle cell anemia
• Adolescent & mental health
• Critical illnesses: sepsis, seizure, DKA
• Prehospital/EMS care

Methodologies
• Complex RCTs
• Prediction modeling
• Risk stratification
• Clinical decision support
• Novel approaches to use of large data
## Foci of PECARN Research

<table>
<thead>
<tr>
<th>Current Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal Saline vs. Lactated Ringers for Pediatric Sepsis</td>
</tr>
<tr>
<td>Azithromycin for Young Children with Wheezing</td>
</tr>
<tr>
<td>Dosing Regimen for Pediatric Seizures in the Prehospital Setting</td>
</tr>
<tr>
<td>Arginine for Sickle Cell Disease Vaso-Occlusive Crisis in Children</td>
</tr>
<tr>
<td>Procalcitonin to Determine Antibiotic Need in Children with Community-Acquired Pneumonia</td>
</tr>
<tr>
<td>Risk Stratification for Emergent Intracranial Abnormalities in Children with Headaches</td>
</tr>
<tr>
<td>Prediction Model for Pulmonary Embolus in Children</td>
</tr>
<tr>
<td>Risk Stratification for Pediatric Cervical Spine Injury</td>
</tr>
<tr>
<td>Pain Control in Children with Long Bone Fractures</td>
</tr>
<tr>
<td>Pediatric Sepsis Screening: Identification of Those at Risk</td>
</tr>
</tbody>
</table>
What about our patients?????

Research-to-Practice Gap

17 Years

It takes 17 years to turn 14% of research into day to day clinical practice!
Pediatric Head Trauma

- 42,412 children enrolled
  - CT Scans: 14,969 (35.3%)
  - Clinically important TBI: 376 (0.9%)

- Rules derived for <2 and ≥2 yrs of age

- Negative Predictive Values
  - <2 yrs: 1176/1176 (100.0%; 99.7-100.0)
  - ≥2 yrs: 3798/3800 (99.95%; 99.81-99.99)

Use of Traumatic Brain Injury Prediction Rules With Clinical Decision Support

Peter S. Dayan, MD, MSc, a Dustin W. Ballard, MD, MBE, b,c Eric Tham, MD, d Jeff M. Hoffman, MD, a Marguerite Swietlik, MSN, RN, f Sara J. Deakyne, MPH, f Evaline A. Alessandrini, MD, MSCE, f Leah Tzimenatos, MD, h,i Lalit Bajaj, MD, MPH, d David R. Vinson, MD, d,j Dustin G. Mark, MD, k Steve R. Offerman, MD, l Uli K. Chettipally, MD, MPH, m Marilyn D. Paterno, MSBI, n Molly H. Schaeffer, MSc, o Jun Wang, MS, p T. Charles Casper, PhD, p Howard S. Goldberg, MD, n,o Robert W. Grundmeier, MD, q Nathan Kuppermann, MD, MPH, h,i for the Pediatric Emergency Care Applied Research Network (PECARN), Clinical Research on Emergency Services and Treatment (CREST) Network, and Partners Healthcare; Traumatic Brain Injury-Knowledge Translation Study Group
### PECARN Pediatric Head Injury/Trauma Algorithm

Predicts need for brain imaging after pediatric head injury.

**INSTRUCTIONS**  
Note: This only applies to children with GCS scores of 14 or greater.

<table>
<thead>
<tr>
<th>When to Use</th>
<th>Pearls/Pitfalls</th>
<th>Why Use</th>
</tr>
</thead>
</table>

#### Age
- **<2 Years**
- **≥2 Years**

#### GCS ≤14, palpable skull fracture or signs of AMS
- **AMS (Agitation, somnolence, repetitive questioning, or slow response to verbal communication)**

#### Occipital, parietal or temporal scalp hematoma; history of LOC ≤5 sec; not acting normally per parent or severe mechanism of injury?
- **Severe mechanism: MVC with patient ejection, death of another passenger, rollover; pedestrian or bicyclist w/o helmet struck by motorized vehicle**

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**PECARN recommends observation over imaging, depending on provider comfort; 0.9% risk of clinically important Traumatic Brain Injury.**

Consider the following when making imaging decisions: Physician experience, worsening signs/symptoms during observation period, age <3 months, parent preference, multiple vs. isolated findings; patients with certain isolated findings (i.e., no other findings suggestive of TBI), such as isolated LOC, isolated headache, isolated vomiting, and certain types of isolated scalp hematomas in infants >3 months have cTBI risk substantially <1%.

Pediatric Head Trauma CT Decision Guide
Children 2 years and older

- GCS < 15
- Signs of basilar skull fracture
- AMS (agitation, somnolence, slow response, repetitive questions)

YES TO ANY
CT
High Risk – 4.3% risk of ci-TBI*

NO

- Vomiting
- LOC
- Severe headache
- Severe mechanism of injury
  - Fall > 5 ft
  - MVA w/ejection, rollover, or fatality
  - Bike/ped vs. vehicle w/o helmet
  - Struck by high-impact object

YES TO ANY
Intermediate Risk – 0.8%
Observation vs. CT using shared decision-making

NO
CT not indicated, Observe
Low Risk – < 0.05%

Clinical factors used to guide decision-making:
- Multiple vs. isolated factors
- Worsening findings during observation (AMS, headache, vomiting)
- Physician experience
- Parental preference

*ci-TBI: risk of clinically important TBI needing acute intervention, based on PECARN validated prediction rules
Application in Practice

Reduction of Computed Tomography Use for Pediatric Closed Head Injury Evaluation at a Non-pediatric Community Emergency Department

Upcoming Development of CDS

• Implementation of ED-based Antimicrobial Stewardship (PI: Mistry)

• Implementation of Febrile Infant Clinical Decision Rule (PIs: Mahajan/Kuppermann)
Datasets and Big Data
PECARN Public Use Datasets

• Federally-funded data released 3 years after lock

• Complete, de-identified study data available

• Currently 15 datasets available for use

https://pecarn.org/datasets/
PECARN Registry Project

• Funded by AHRQ in 2012

• Objective: Create medical record registry via compete EHR data extraction from multiple sites

• Potential Uses
  • Grant preparation and future research
  • Quality improvement
  • Funded research
    • Predictive modeling, risk assessment, machine learning
    • Comparative effectiveness
    • Linked for prospective enrollment

PECARN Registry

• Participating EDs
  • Initially 4 sites; now 12
  • 10 Epic EHR and 2 Cerner

• Complete EHR ED visits

• Transfers monthly to DCC

Cumulative Totals 2012-2020

<table>
<thead>
<tr>
<th>Data point</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sites</td>
<td>12</td>
</tr>
<tr>
<td>Encounters</td>
<td>5,184,410</td>
</tr>
<tr>
<td>Patients</td>
<td>1,918,346</td>
</tr>
<tr>
<td>Diagnoses</td>
<td>21,843,323</td>
</tr>
<tr>
<td>Lab Tests</td>
<td>5,272,065</td>
</tr>
<tr>
<td>Lab Results</td>
<td>38,621,682</td>
</tr>
<tr>
<td>Microbiology Tests</td>
<td>2,184,617</td>
</tr>
<tr>
<td>Microbiology Results</td>
<td>2,842,939</td>
</tr>
<tr>
<td>Medication Orders</td>
<td>7,294,339</td>
</tr>
<tr>
<td>Medication Administrations</td>
<td>7,959,884</td>
</tr>
<tr>
<td>Radiology Tests</td>
<td>1,990,308</td>
</tr>
<tr>
<td>Narrative Documents</td>
<td>28,105,263</td>
</tr>
<tr>
<td>Providers included in report cards</td>
<td>1,643</td>
</tr>
</tbody>
</table>

PECARN Registry Variables

- **Patient Identifiers:** Patient number, encounter number
- **Demographics:** Date of birth (DOB), sex, race, ethnicity, zip, payer
- **Visit Information:** Triage category, chief complaint, arrival mode
- **Date/Time:** notification, ED door, sort/triage, discharge
- **Providers:** Provider ID, provider role, provider D/T
- **Vitals:** Vitals D/T, T, HR, RR, SBP, DBP, oxygen saturation, weight
- **Medications:** Current; ED (D/T); discharge
- **Clinical Assessments:** Asthma score, Pain score, Glasgow Coma Scale (GCS)
- **Narrative:** Narrative D/T, author type, narrative
- **Radiology:** Order D/T, start D/T, avail D/T, report D/T, report
- **Labs (including Micro):** Lab D/T result
- **Procedures:** CPT, ICD9, ICD10
- **Diagnosis:** ICD9, e-codes, ICD10
- **Disposition:** ED disposition, Hospital discharge D/T, Vital status
PECARN Registry: Data Flow

1. Data Maturation
   - Week 4 through 4
   - Data are gathered 4 weeks following the end of the month to "mature"

2. Data Extraction
   - All the end of week 4 sites create their data extract in XML format

3. Data Submission
   - Sites have 5 business days to submit
   - Beginning the first business day following data maturation

4. QA Review
   - During week 5, the site PI's review QA reports that are auto-generated in SharePoint

5. Data Resubmissions (as needed)
   - All data due by end of Week 5

6. Data Grouping
   - Sites review provider grouping and Study PI reviews needs grouping
   - Due 2 days after data lock

7. Report Cards
   - Report card generation happens in Week 7, and are sent Week 8
Bringing Registry Data to the Provider

• Automated feedback
  • Associated with improvements in care
  • Assists with sustainability of change

• Report cards
Monthly Site Report Cards

Systemic corticosteroids given in the ED

<table>
<thead>
<tr>
<th>Site</th>
<th>Percentage (N=52)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network</td>
<td>92.2%</td>
</tr>
<tr>
<td>ABC</td>
<td>98.3%</td>
</tr>
</tbody>
</table>

Time (min) to first beta-agonist treatment

<table>
<thead>
<tr>
<th>Site (med[IQR])</th>
<th>44 [30,60] (N=52)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network (med[IQR])</td>
<td>46 [20,72]</td>
</tr>
<tr>
<td>ABC</td>
<td>27</td>
</tr>
</tbody>
</table>

Asthma score documented while in the ED

<table>
<thead>
<tr>
<th>Site</th>
<th>Percentage (N=52)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network</td>
<td>90.6%</td>
</tr>
<tr>
<td>ABC</td>
<td>100%</td>
</tr>
</tbody>
</table>
Respiratory Diseases (Asthma): All Respiratory Diseases performance measures include only visits of patients ≥ 2 years of age with an asthma diagnosis and 2 or more doses of beta-agonist (based on weight) given in the ED (regardless of disposition except where noted).

Systemic corticosteroids given in the ED:

- You: 90% (N=30)
  - Your Site: 87.3%
  - Network: 89.2%
  - Site ABC: 98.2%
  - Network ABC: 98.5%

Time (min) to first beta-agonist treatment:

- You: 72 [37,111] (N=30)
- Your Site: 53 [29,108]
- Network: 50 [29,87]
- Site ABC: 28
- Network ABC: 27
PECARN Registry: Process

Patient EHR
All ED Visits
Monthly Data Transmission

Validation
De-identification

Data Coordinating Center

PECARN Registry

Natural Language Processing (NLP)
Performance Measures

Benchmarks
Site specific
Provider specific

Improved Patient Care; Evidence-based Research

PECARN Registry: Process

PECARN

Performance Measures

Benchmarks
Site specific
Provider specific
PECARN Registry Funding

• AHRQ Funded 2011-2015

• Current Ongoing Funding
  • Data Coordinating Center
  • Project funding
  • Participating sites: Annual fee

• Project specific grant funding
  • Validation of new variables
  • Data management
  • Statistical analysis
PECARN Registry Related/Linked Studies

**PED Screen**
- **R01HD087363 (Elizabeth Alpern)**
  - Pediatric Sepsis EHR Registry, Clinical Outcomes, and Predictive Model Research Strategy.
  - This study will create a multi-centered pediatric emergency care sepsis registry derived from EHR data, develop and validate methods to identify children at risk of severe sepsis, and develop predictive model to identify patients at risk of developing sepsis.

**IMPROVE**
- **R01HD091302 (Amy Drendel)**
  - The Effect of Emergency Department and After-Emergency Department Analgesic Treatment on Pediatric Long Bone Fracture Outcomes.
  - The overall goal is to evaluate and provide evidence for both ED and post-ED pain treatment for all children with acute fracture-related pain. Uniquely, this study prospectively tracks the full patient experience from ED visit to home.

**SCIENCE**
- **U01HL143477 (David Brousseau)**
  - Implementation of evidence-based care for the acute treatment of sickle cell disease pain.
  - Identify the barriers and facilitators to NHLBI guideline adherent care for pain in SCD, allowing for successful design of a multi-center hybrid 3 implementation trial to improve the experience of children with SCD presenting in acute pain.

**Disparities in ED Care**
- **R03MD011654 (Monika Goyal)**
  - Detecting Racial and Ethnic Disparities in Pediatric Emergency Care Using the PECARN Data Registry.
  - Detect and document racial and ethnic disparities in the management of acute pain among children presenting to emergency departments (ED) with long bone fractures and those diagnosed with appendicitis.
Thank you!!!!

• Acknowledgments
  Elizabeth R. Alpern, MD, MSCE
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  Lalit Bajaj, MD, MPH
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  Kathleen Adelgais, MD, MPH
  Jennifer Sadlowski
  Gonzalo Lerner
  Kathleen Grice
  Mimi Munroe
Pediatric Emergency Research Networks

• Global network of networks

• 8 member PEM networks

• Studies
  • H1N1 pandemic
  • Practice patterns
  • COVID-19 pandemic

UTI CDS Appearance
When you enter the impression the CDS “activates”

In the background, when a UA is ordered, the CDS is triggered for activation, but you will not know
Broad impressions will activate (e.g. UTI, Pyelo, Cystits)

New CDS orderset populates

BPA box with guideline info and active links if desired
When orderset checked, only correct choice displayed

“Correct” choices based on patient age, presence of allergy, and presence of fever

Antibiotic prescription fully prepopulated for dose and duration. You only need to “sign”!!!!
No need to open prescription, but this is how it appears with pre-populated data.
Technology has been developed to extract data for all emergency department visits, accomplish substantial de-identification of the extract prior to transmission to the Data Coordinating Center (DCC), and produce a data warehouse registry to use for quality improvement and research.

Quality Assurance: Comprehensive data quality assurance rules are automated to assess data quality and validation of the transmitted data. Monthly data quality reports are constructed for each site by month and entire year data breakdown to facilitate effective and efficient data quality review.

Report Cards: Data from the Registry is used to assess stakeholder prioritized quality of care performance measures and determine benchmarks for the metrics. Site-level report cards are populated from the Registry and distributed monthly and semi-annually. Provider-level report cards are distributed semi-annually.

Benefits:
- Captures ALL patients to ED
- Captures wide range of data (EHR reality; includes text)
- ED specific data (lacking in many other sources)
- Allows for organization of data to facilitate analysis
- Allows for ongoing temporal collection of data leading to responsive analysis (Network-level, Site-level)
- Allows for active linkage for prospective studies
- Innovative grants with proven success
- Scalable (3 waves of entry) and maintainable (reasonable IT effort)

Challenges:
- EHRs are ever-changing
- Each new site that joins is going to have a new challenge or identify a problem that every prior site missed
- Site ongoing IT collaboration
- Consistence of staffing over time