Creating a Learning Health System: Translating Research into the Standard of Care

William E. Smoyer, M.D.
C. Robert Kidder Chair,
Vice President and Director,
Center for Clinical and Translational Research
The Research Institute at Nationwide Children’s Hospital
Professor of Pediatrics, The Ohio State University

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Overview

• Summarize major trends and barriers to integrating clinical care and research

• Suggest a Learning Health System paradigm shift

• Describe the “Learn from Every Patient” (LFEP) program model and structure

• Share NCH experience with a LFEP Pilot Program

• Share lessons learned and opportunities!
Introduction

• Convergence of three major trends in medicine
  • Conversion to electronic medical records
  • Prioritization of translational research (in part via CTSA)
  • Increasing need to control healthcare expenditures
• Unprecedented interest and opportunities to develop systems that improve care while reducing costs
• Significant Barriers to Development of “Learning Health Systems”
  • Inadequate organizational readiness
  • Inadequate information standards
  • Inadequate technology integration
  • Inadequate workflow integration (clin vs. res processes / cultures)
## Misalignment of Health System Interests

### Varying Interests of Key Stakeholders

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Primary Interests</th>
</tr>
</thead>
<tbody>
<tr>
<td>CEO (Chief Executive Officer)</td>
<td>Reputation / Quality Care / Efficiency</td>
</tr>
<tr>
<td>CMO (Chief Medical Officer)</td>
<td>Medical Staff Administration / Peer Review</td>
</tr>
<tr>
<td>COO (Chief Operating Officer)</td>
<td>Efficiency / Improved Value</td>
</tr>
<tr>
<td>CQO (Chief Quality Officer)</td>
<td>Quality Improvement / Patient Safety</td>
</tr>
<tr>
<td>CIO (Chief Information Officer)</td>
<td>Efficiency / Data Governance</td>
</tr>
<tr>
<td>CFO (Chief Financial Officer)</td>
<td>Lower Care Costs / Increased Patient Volume</td>
</tr>
<tr>
<td>CRIIO (Chief Research Information Officer)</td>
<td>Discrete Data Points / Data Interfaces / Data Accessibility</td>
</tr>
<tr>
<td>CMIO (Chief Medical Information Officer)</td>
<td>Usability of Medical Record / Quality of Care</td>
</tr>
<tr>
<td>Physicians</td>
<td>Best Care / Opportunity to Improve Care</td>
</tr>
<tr>
<td>Nurses</td>
<td>Ease of Documentation / Clear Care Guidelines</td>
</tr>
<tr>
<td>Hospital Staff</td>
<td>Standardized Care / Ease of Documentation</td>
</tr>
<tr>
<td>Policy Makers</td>
<td>Cost Containment / Improved Value</td>
</tr>
<tr>
<td>Health IT Vendors</td>
<td>Profitability / Data Accessibility</td>
</tr>
<tr>
<td>Risk Management</td>
<td>HIPAA Privacy / Data Integrity</td>
</tr>
<tr>
<td>Patients and Families</td>
<td>Quality of Care / Patient Satisfaction</td>
</tr>
</tbody>
</table>

Learning Health System Paradigm Shift

CURRENT STATE WITH CURRENT PARADIGM

CEO
CMO
COO
CFO
CIO
CRIO
CMIO
NURSES
HOSPITAL STAFF
POLICY MAKERS
RISK MANAGEMENT
PATIENTS & FAMILIES

• INCONSISTENT CARE
• RISING COSTS
• VARIABLE QUALITY
• POOR VALUE

FUTURE STATE WITH LEARNING HEALTH SYSTEM PARADIGM

CEO
CMO
COO
CIO
CRIO
CMIO
NURSES
HOSPITAL STAFF
POLICY MAKERS
HEALTH IT VENDORS
PATIENTS & FAMILIES

• BETTER CARE
• LOWER COSTS
• IMPROVED QUALITY
• BETTER VALUE

DISRUPTIVE INNOVATION
EVIDENCE BASED MEDICINE
EVIDENCE GENERATING MEDICINE

HEADWINDS
“Bottom Up” Approach to Create a Learning Health System
**Hypothesis:** A “Learning Health System” can be cost-effectively developed and implemented to systematically drive both clinical quality improvement and reduced healthcare costs.

**Aim:** To develop and implement a pilot program based on full integration of research and clinical care.

“Learn From Every Patient™” Program
“Learn From Every Patient” Program Model

- Patient-Related Data Sets (Proteomics, Genomics, Metabolomics, etc.)
- Clinical+Research Data Collection Integrated into Provision of Care
- Data from Clinical and Research Sources Systematically Analyzed

- Patients Receive Evidence-Based Standardized Care
- Systematic Application of Improvements to Care of All Patients

- “Learn From Every Patient” Program Model

- Quality Improvement

- Translational Research
  - New Knowledge Drives Incremental Improvements in Cost Effectiveness and Standards of Care
  - Peer Reviewed Publications (Dissemination of New Knowledge)

Nationwide Children’s
When your child needs a hospital, everything matters.

Ohio State University
College of Medicine
Perspective on LFEP Program...

“... inspiration is easy. Implementation is the hard part.”

Bob Taylor (Taylor Guitars)
Building the Team

• Pilot Program Identified
  • Cerebral Palsy Program
    • Small / Charged with “improving clinical care”

• Key Stakeholders for Pilot Program Identified
  • Physicians / Nurses / Clinical staff
  • Program administrators
  • Hospital EMR (EPIC) team
  • Enterprise Data Warehouse (EDW) team
  • Research informatics systems (RIS) team
  • Hospital informatics systems (HIS) team
  • Patient / Parent input (through MPOC survey)

• Project Manager Recruited
Setting Expectations

• Biweekly meetings convened
• Scope of LFEP program detailed for CP Program
  • Advantage: EMR had not yet been rolled out in program
• Benefits to organization and patients emphasized
• Individual expectations for roles in program clarified
  • Altered clinical practices required for physicians
  • Altered clinical practices required for nurses / staff
  • Altered interactions between hospital and research informatics teams
  • Altered rollout of EMR (“We’ve never done this…”)

• “This is a lot of change !!!”
Perspective on LFEP Program…

“Change is hard because people overestimate the value of what they have - and underestimate the value of what they may gain by giving that up.”

James Belasco and Ralph Stayer
“Flight of the Buffalo”
Project Management

• IRB Database Protocol Created
• Routine clinical care-related data fields developed (per standard process)
• “Clinical care team” charged with several key tasks:
  • Commit to initial standard of care (evidence + opinion-based)
  • Determine three high-value research questions that would advance their field
  • Develop research data fields to collect key info for above
  • Develop research data elements to populate these fields
• Hospital EMR team charged with building these into EMR
• Clinical team in-serviced for clinical / research data entry
LFEP Pilot Program

• **Hypothesis**: A “Learning Health System” can be cost-effectively developed and implemented to systematically drive both clinical quality improvement and reduced healthcare costs

• Developed, implemented, and evaluated a model of EHR-supported care in a cohort of 131 children with CP which integrates:
  • Clinical care
  • Quality improvement
  • Research

• Compared changes in healthcare utilization rates and healthcare charges
LFEP Intervention

• LFEP Group (During Study Period):
  • Initial Standardized Care provided to all patients
    • Evidence + Expert Opinion-based
  • Routine clinical data collected in EMR
    • Discrete data fields (categories)
    • Discrete data elements (choices within category)
  • Physician-inspired research data collected in EMR
  • Content-specific quality control of EMR data entry
    • Standard Care Coordination provided

• Non-LFEP Group:
  • Standard of care at NCH (but not standardized)
  • Standard Care Coordination provided
Comparison of Changes in Healthcare Utilization Rates (%)

Figure 2

Comparison of Changes in Healthcare Charges ($)

Comparison of Changes in Healthcare Charges (%)

Changes in Healthcare Utilization Rates and Charges

• 43% reduction in total inpatient days
  • 351 vs. 612 days ($P=0.031$ vs. prior 12-month period)
• 27% reduction in inpatient admissions
  • 72 vs. 98 admissions
• 34% reduction in total inpatient charges
  • $1.33$ M ($10,151$ per child)
• **Incremental** reductions in total healthcare charges
  • 210% vs. Pre-LFEP Group (Time Control)
  • 176% vs. Non-LFEP Group (LFEP Program Activities Control)
“Learn From Every Patient” Program Model

- Patient-Related Data Sets (Proteomics, Genomics, Metabolomics, etc.)
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- Data from Clinical and Research Sources Systematically Analyzed

Patients Receive Evidence-Based Standardized Care

- Systematic Application of Improvements to Care of All Patients

“Learn From Every Patient” Program Model

Translational Research

- New Knowledge Drives Incremental Improvements in Cost Effectiveness and Standards of Care

Quality Improvement

Peer Reviewed Publications (Dissemination of New Knowledge)

Figure 1

Nationwide Children's
When your child needs a hospital, everything matters.

The Ohio State University
College of Medicine
LFEP "Learning Projects" Underway

<table>
<thead>
<tr>
<th>LFEP Research Questions</th>
<th>Research Progress to Date</th>
<th>Direct Impact on Clinical Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are routine hip films useful for screening all children with CP?</td>
<td>Data collected and analyzed Manuscript in preparation</td>
<td>Altered practice patterns already implemented to reduce hip X-rays in patients with mild CP</td>
</tr>
<tr>
<td>Does the use of prophylactic tobramycin improve the health of children with tracheostomies?</td>
<td>Data collected and analyzed Abstract accepted Manuscript in preparation</td>
<td>Clinical care changes to be implemented pending results</td>
</tr>
<tr>
<td>Is the Communication Functional Classification Scale (CFCS) stable over time?</td>
<td>Data collected and analyzed Abstract presented Manuscript in preparation</td>
<td>LFEP Program in first 12 months completed more evaluations with this scale than any other program in US</td>
</tr>
<tr>
<td>Should children with CP and severe GE reflux undergo a Nissen or have a GJ tube inserted?</td>
<td>Data collected and under analysis</td>
<td>Clinical care changes to be implemented pending results</td>
</tr>
<tr>
<td>What do CP patients’ parents feel are the most burdensome aspects of care?</td>
<td>Data collected Abstract presented Manuscript Published</td>
<td>New programs already implemented to address identified family concerns</td>
</tr>
</tbody>
</table>

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LFEP Program Summary

• Results demonstrate that a “Learning Health System” can be developed and implemented in a cost-effective manner
  • Costs ($225K) ~16% of first-year cost reduction ($6 saved/$1 spent)
• Such programs can systematically drive simultaneous clinical quality improvement and reduced healthcare costs
• Broad-based “buy-in” essential for programmatic success
  • Clinical / Research / Financial / Political
• “Integration” requires significant culture change !!!
  • Physicians (drop-down menus; radio buttons; etc.)
  • Nurses (documentation; etc.)
  • Clinical Staff (documentation; etc.)
  • Administrators (clinic flow; charge documentation; etc.)
LFEP Program Summary

• **Huge** opportunities for those willing / able to change!
  - Systematic improvement in clinical care
  - Reductions in healthcare expenditures
  - Expected market advantage for robust delivery of evidence-based care
  - Unprecedented phenotyping of biologic samples
    - Genomics / Proteomics / Metabolomics / Transcriptomics
  - Incorporation of Patient-Reported Outcomes (PROs)
  - Career advancement of academic faculty (Publications)

• LFEP model ideally suited for Accountable Care Organizations (ACOs)
Future Challenges for LFEP Program

• Is the LFEP Program scalable?
• Can LFEP be successfully applied to adult care?
• Can LFEP be successfully applied to surgical care?
• Is LFEP transferable to other institutions?

• These are testable questions!
• We are interested in answering them!
Final Perspective on LFEP …

“Progress is impossible without change: And those who cannot change their minds cannot change anything.”

George Bernard Shaw, Irish playwright
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• Lamara Love, BSN
• Abigail Tidball, PT
Key Activities for LFEP Program

5 Major Components

• Implementation / Ongoing Oversight
• Development of EMR [EPIC (“Clarity”)] fields
• Data Mart Build
• Data Extraction
• Reporting Tool
Key Positions for LFEP Program

• LFEP Project Manager
• Research EMR Specialist
• Research EDW Specialist
• Report Specialist
• Data Quality Specialist / Point-of-Care Support