

The Role of Registries and Collaboratives in Improving Pediatric Care

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Objectives

- Describe the types of registries and collaboratives in use in pediatric care and recognize the role of inter-institutional collaboration in making them successful.
- Understand the impact of these registries and collaboratives on improving quality of care in pediatrics.
- Identify examples of quality improvement and patient safety advancements that have resulted from some of the current registries and collaboratives at Connecticut Children's Medical Center.

Disclosures

- None

“Improving Pediatric Care”

- The Institute of Medicine defines healthcare quality as:

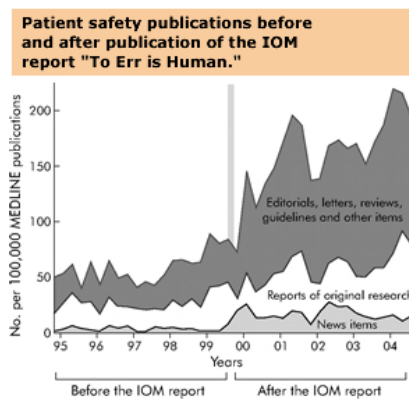
The extent to which health services provided to individuals and patient populations improve desired health outcomes

Institute of Medicine (IOM). 2001. Crossing the Quality Chasm. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C: National Academy Press.

“Improving Pediatric Care”

- “Patient Safety and Quality Improvement” field has gained increased attention and awareness over past 15 years

- Why?



Patient safety publications before and after publication of the IOM report “To Err is Human”. Agency for Healthcare Research and Quality Patient Safety Network website. Retrieved from: <https://psnet.ahrq.gov>



- Published by the Institute of Medicine in 1999

“At least 44,000 people, and perhaps as many as 98,000 people, die in hospitals each year as a result of medical errors that could have been prevented”. (IOM Report, 1999)

Institute of Medicine (IOM). 2000. To Err Is Human: Building a Safer Health System. L. T. Kohn, J. M. Corrigan, and M. S. Donaldson, eds. Washington, D.C: National Academy Press.

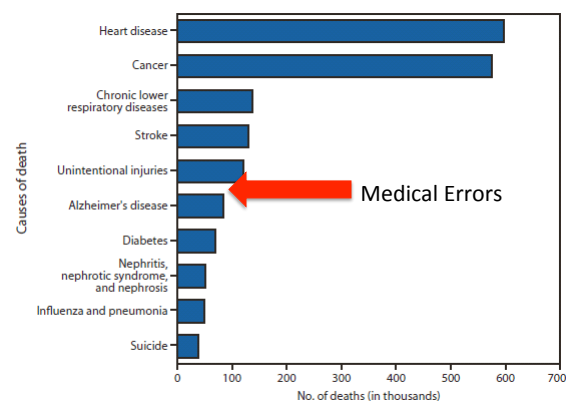


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2 fully loaded Boeing 737 airliner crashes **every day**
from **preventable** harm



Burden of Medical Errors



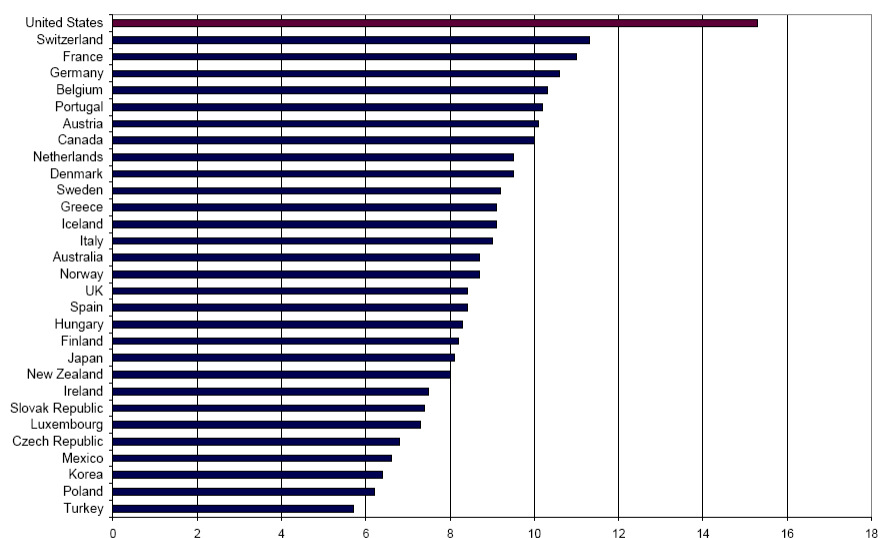
Murphy SL, Xu JQ, Kochanek KD. QuickStats: Number of Deaths from 10 Leading Causes — National Vital Statistics System, United States, 2010. 2013, March 1;62(08):155. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6208a8.htm>

Burden of Medical Errors

- Annual cost of measurable medical errors that harm patients = \$17.1 billion

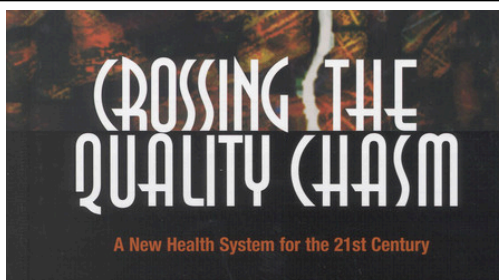
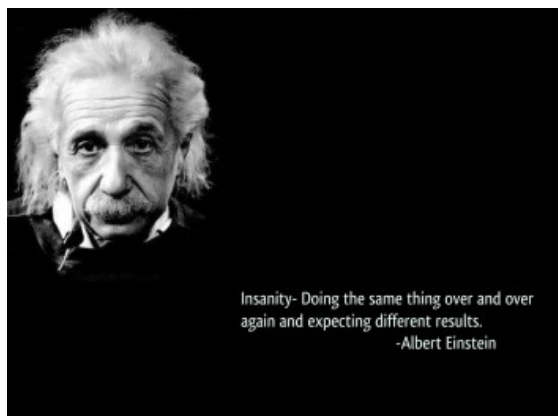
Condition	Cost per Event
CLA-BSI	\$31,000
VTE - (post surgery)	\$8,000
Pressure Ulcer	\$43,000
SSI	\$27,000
VAP	\$51,000
CA-UTI	\$1,000
ADE	\$5,000
Injury from Fall	\$13,000
Readmissions	\$9,540
SSEs	\$440,000
Codes (outside ICU)	\$50,000

Healthcare Spending as % GDP



Source: Organization for Economic Cooperation and Development, OECD Health Data, 2008 (Paris: OECD, 2008).
 Note: For countries not reporting 2006 data, data from previous years is substituted.

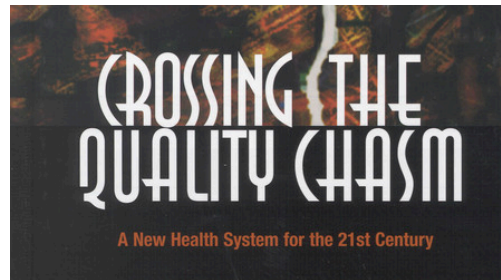
What can we do about it?



- Published by the Institute of Medicine in 2001

“Between the health care we have and the care we could have lies not just a gap, but a chasm.”

Institute of Medicine (IOM). 2001. Crossing the Quality Chasm. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C: National Academy Press.



- Report identified 6 aims for improvement:
 - Safe – no needless deaths
 - Effective – no needless pain or suffering
 - Patient-Centered – no helplessness in those served or serving
 - Timely – no unwanted waiting
 - Efficient – no waste
 - Equitable – for all

Institute of Medicine (IOM). 2001. Crossing the Quality Chasm. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C: National Academy Press.

Quality Improvement in Healthcare

- Since IOM reports, healthcare industry has been working to improve patient safety and quality in healthcare settings.



IHI Triple Aim Initiative. Institute for Healthcare Improvement. Retrieved from <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>

Quality Improvement in Healthcare

- Key components for improvement:
 - Decision making is evidence-based, with protocols & process support
 - Care delivery is Team-based
 - **Cooperation** among the clinicians is a priority
 - **Knowledge is shared** and information flows freely
 - **Transparency** is a necessity

Quality Improvement in Healthcare

- Individual pediatric clinicians, practices and institutions working to improve, but transparency and knowledge sharing is paramount for advancement

Improving quality of care in pediatrics

- Knowledge sharing is particularly important in pediatrics:
 - Pediatric diseases are generally rare (NIH prevalence of <200,000 in US)
 - Few practices/centers have enough volume to achieve reliable sample sizes for evaluating care
 - Care between sites is extremely variable
- Collaboratives and registries critical in knowledge sharing and quality improvement mission

Lannon CM, Peterson LE. Pediatric Collaborative Networks for Quality Improvement and Research. *Academic Pediatrics*. 2013;13:S69-S74

Pediatric Collaborative Improvement Networks

- Multisite clinical networks
- Apply scientific methods and structured approach to the design, development and testing of improvements and innovations.
- Allow practice-based teams to learn from one another, test changes to improve quality, use collective experience and data to implement and spread new “best practices”
- Achieve improvements at lower cost, more efficiently, and faster than any single hospital or provider can achieve independently

Clancy CM, Margolis PA, Miller M. Collaborative networks for both improvement and research. *Pediatrics*. 2013;131:S210-S214

Pediatric Collaborative Improvement Networks: Features

- Focus on outcomes: clear aims and measurable data-driven targets
- Evidence-based
- Apply scientific methods (quality improvement methodologies, qualitative research, system science)
- Utilize technology effectively: infrastructure support for data collection, analysis and reporting
- Obtain support from experts (clinical and quality) for guidance, training, and ongoing coaching and support
- Create a series of defined collaborative activities
- Engage multidisciplinary teams from multiple sites and include patients and families as co-owners of the work
- Provide strong foundation for research

Example 1: The Children's Hospitals Solutions for Patient Safety

History:

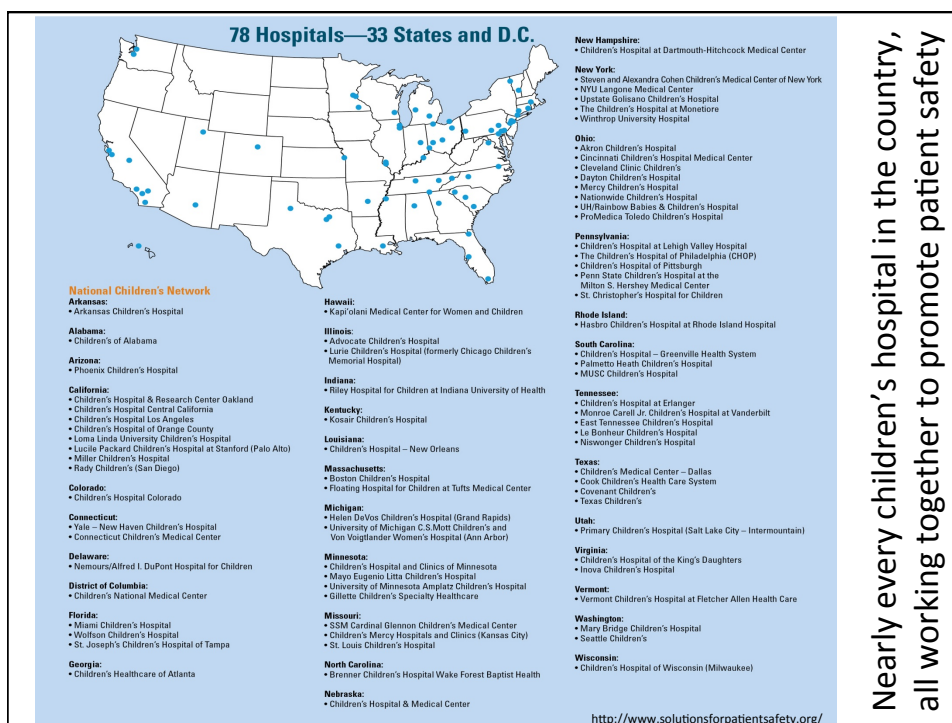
- January, 2009, the 8 children's hospitals in Ohio banded together to improve care and reduce costs for pediatric patients in the state
 - Mission: To work together to eliminate serious harm across all children's hospitals
- 3 principles:
 - We will not compete on safety
 - Full transparency for safety-related data-sharing
 - “All teach all learn” model

Solutions for Patient Safety

"The goal was, if we pooled our data and resources, ultimately we'd all benefit by figuring out best practices and making care safer, cost effective and with better outcomes."

- During first 3 years, state-wide collaborative was hugely successful:
 - Reduced surgical site infections in cardiac, neurosurgery and orthopedic procedures by 40%
 - Reduced adverse drug events by 42%
- Initial work was so successful, the group was asked to expand nationally, broaden scope
 - CMS-funded (Partnership for Patients federal initiative)
 - Only pediatric Hospital Engagement Network

MacDonald J. Competing hospitals work together to share data, improve patient safety. Fierce Healthcare. February 20, 2015. Retrieved from <http://www.fiercehealthcare.com/story/competing-hospitals-work-together-share-data-improve-patient-safety/2015-02-20>



Solutions for Patient Safety Goals

- Goal is to create high reliability organizations through basic principles of transparency and non-competition
- Current targets:
 - 40% reduction in hospital acquired conditions
(1.8 million fewer injuries, more than 60,000 lives saved over 3 years)
 - 20% reduction in hospital readmissions
(1.6 million patients could avoid re-hospitalization over 3 years)
 - 25% reduction in serious safety event rate
- How?

<http://www.solutionsforpatientsafety.org/>

What do they do?

- Help to create a culture of safety
- Identify best practices used by high performers and encourage the adoption of those measures everywhere
 - Over 225 webinars
 - Over 60 work groups
 - Multiple national learning sessions
- Encourage and teach use of “bundles” to reduce HACs:

A series of small-scale interventions that, combined, reduce multiple common harms (infections, adverse drug events and falls)

 - Every hospital posts open data on outcomes and bundle adherence

How a pediatric hospital collaborative transformed patient safety: Ohio Hospital children's hospitals used noncompetitive structure, transparency to create "culture of safety". Budryk, Z. Fierce HealthCare. 2015, June 29. Retrieved from <http://www.fiercehealthcare.com/story/how-pediatric-hospital-collaborative-transformed-patient-safety/2015-06-29>

Hospital Acquired Conditions

- Adverse Drug Events (ADE)
- Catheter-Associated Urinary Tract Infections (CAUTI)
- Central Line-Associated Blood Stream Infections (CLABSI)
- Injuries from Falls
- Pressure Ulcers (PU)
- Surgical Site Infections (SSI)
- Ventilator-Associated Pneumonia (VAP)
- Preventable Readmissions
- Venous Thromboembolism (VTE)
- Serious Safety Events (SSE)

What has been accomplished?

- In 4 years since national initiative began:
 - Decrease in HACs between 1-81%
 - Prevention of harm during hospitalization for estimated 3,699 children
 - Savings of an estimated \$79,189,000

"We aren't out to compete in patient safety...
Everyone is a teacher, everyone is a student."

Cox, E. Patient Safety in Children's Hospitals: The Journey to Zero Harm. U.S. children's hospitals are uniting to improve patient safety. Will adult health care follow suit? US News and World Report Health. 2015, June 29. Retrieved from <http://health.usnews.com/health-news/patient-advice/articles/2015/06/29/patient-safety-in-childrens-hospitals-the-journey-to-zero-harm>

MacDonald, I. Competing hospitals work together to share data, improve patient safety. Fierce Healthcare. 2015, February 20. Retrieved from <http://www.fiercehealthcare.com/story/competing-hospitals-work-together-share-data-improve-patient-safety/2015-02-20>

Other Examples: Children's Hospital Association Quality Improvement Collaborative

- Large network of children's hospitals working to improve patient care and safety, spread innovations, and identify new strategies to improve hospital care.
- Network helps to create framework and system for outcome measurement and long-term sustainability
- Examples of collaboratives within network:
 - Childhood Cancer and Blood Disorders Learning Network
 - Standardizing Care to Improve Outcomes in Pediatric ESRD (SCOPE) Collaborative
 - Sepsis Collaborative
 - Standardizing Transitions and Euthermia (STEPP IN) – aims to reduce postop hypothermia and failures in neonates

Quality Improvement Registries

- Enable systematic data collection of individual and population-level data to improve patient care
- Defined by the area of focus, population, outcome measures of interest, level of reporting
- Registries generally exist for 2 major categories:
 - Patients exposed to particular health services (receiving procedure or hospitalization for particular condition)
 - Patients with a disease/condition tracked over time
- Local, regional, national, and international
- Support improved quality of care via more detailed information from aggregate experience
 - Track a wide variety of patient characteristics, exposures, treatments and outcomes
 - Allow comparisons and conclusions to be reached about best practices

Quality Improvement Registries . "Registries for Evaluating Patient Outcomes: A User's Guide 3rd Ed.

Different from classic research registries

QI Registries	Research Registries
Identify clearly defined quality measures (ie. surgical site infections) and collect necessary data to calculate measure at provider, institution or system level	Identify key research questions and collect data necessary to address those questions
No predetermined enrollment and no specified end time – the more the better	Specified number of patients over specified timeframe
Promote rapid cycle improvement via continuously calculating and sharing participant performance and encouraging change	Track and record specific, set data, which is often not analyzed until the completion of data collection, with change not allowed
Sites typically pay a participation fee – in return for tools, reports, improved care and outcomes, recognition	Sites often receive compensation for entering patients

Leavy M, Campion DM. Designing quality improvement registries. *Applied Clinical Trials*. April 3, 2015.

Quality Improvement Registries

- Key features:
 - Collegial
 - Non competitive
 - Evidence based
 - Broad participation from committed multi-disciplinary teams
- Benefits of participation include:
 - Identifying quality improvement targets
 - Improving patient care and outcomes
 - Decreasing institutional healthcare costs



Campbell D. A Culture in Support of Transparency. Presentation at LLI Annual Forum. September 17, 2015. Boston, MA.

Registries: Methodology

- Develop a registry
- Use registry to examine variation in quality
- Identify best performing hospitals
- Identify “best practices” in the best performing hospitals
- Distribute the information
- Track the data

Do they work?

Example:



**American College of Surgeons National Surgical
Quality Improvement Pediatric Program**



- Data-driven, risk-adjusted, outcomes-based program to measure and improve the quality of surgical care
- Program uses clinical data to assess outcomes 30 days after index surgery
- Highly standardized and validated data definitions

Tracks many different variables and outcomes of interest

- Preoperative data
 - Demographics
 - Clinical laboratory variables
- Intraoperative data
 - Surgical profile
 - Clinical variables and complications
- Postoperative data
 - 30-day outcomes (inpatient and outpatient)
 - Complications and discharge variables
- Custom fields
 - Allow sites to create their own variables for internal tracking and evaluation

Outcome models

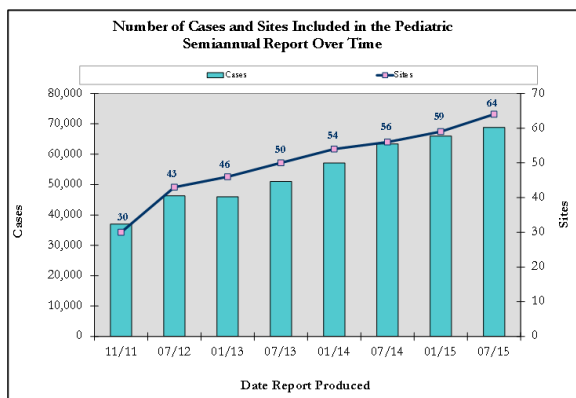


All Surgery Types in All Patients:

- Mortality
 - Morbidity
 - SSI
 - DVT
 - Re-intubation
 - Cardiac
 - Pneumonia
 - Renal
 - UTI
- Also broken down by:
 - Type of surgery (abdominal)
 - Surgical sub-specialty (general surgery, orthopedics, ENT, plastic surgery, neurosurgery, urology)



- 68,838 cases submitted in CY 2014



NSQIP Quarterly Report, July, 2015.

Spreading change

- Best performing hospitals report on their practice methods and tools
- Other sites take recommendations and tools home, implement, and new data reviewed
- Cycle repeats...



- Current initiatives:
 - Unnecessary antibiotic use in clean cases
 - Neurosurgery wound closure algorithm
 - Orthopedic surgical site infection bundle
 - Spine surgery blood transfusion study
 - Spine surgery pilot data collection

About the money...

- Registries and collaborative networks improve quality, safety and are essential to continual improvement
- But they cost money:
 - SPS: \$30,000/year
 - CHA: \$25,000/year
 - NSQIP: \$30,000/year
- Are they financially smart?



About the money...

	Hospital costs	Negative effects on contribution margin
Temporary harm during hospitalization	\$2,187	\$669
Lasting/serious harm during hospitalization	\$4,617	\$1,112
Total 21,000 patients in 24 hospitals for 4 years	\$108 million saved	\$18 million saved
Healing our patients while keeping them safe	Priceless	

Adler L, Yi D, Li M, et al. Impact of Inpatient Harms on Hospital Finances and Patient Clinical Outcomes. Journal of Patient Safety: 2015;00:00-00.

The Patient Perspective

Don't harm me

Heal me

Be nice to me

...in that order



(imagine your loved one here)

Registries and Collaboratives: Conclusion

- Allow sharing of data and experiences to improve and spread best practice.
- Reduce unnecessary variation in care and outcomes, leading to decreased costs.
- Provide stable infrastructure and systems for sustainability and continual testing of new ideas and strategies.
- Proven and transforming principle in pediatrics, requiring ongoing participation and support.



Lannon CM, Peterson LE. Pediatric Collaborative Networks for Quality Improvement and Research. Academic Pediatrics. 2013;13:S69-S74

The Institute of Medicine promotes:

“Learning Healthcare Systems in which knowledge generation is so embedded into the core of the practice of medicine that it is a natural outgrowth and product of the health care delivery process and leads to continual improvement in care”



Institute of Medicine. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. Washington DC: The National Academies Press; September 2012.
Clancy CM, Margolis PA, Miller M. Collaborative networks for both improvement and research. *Pediatrics*. 2013;131:S210-S214

Questions?



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