Experience-based co-design to improve care processes for newly diagnosed children with cancer

MUHC ISAI Conference

Partnering with patients to improve care: Essential skills and strategies

Montreal, Quebec

October 30, 2015
• Children’s Hospital of Eastern Ontario (CHEO)
  – an academic pediatric health science centre providing care for children and youth aged 0 to 18
  – 2,500 staff, 6,200 admissions, 7,000 surgeries, 170,000 clinic visits and over 65,000 emergency room visits yearly
  – also runs specialized programs for eating disorders, autism, psychiatric mental health, sexual assault, telepsychiatry and early language development

• Senior leaders and family advisors looking for ways to systematically engage patients/families in the identification of quality issues and in the design and implementation of solutions

• Prioritization exercise led by Family Forum selected Experience Based Co-Design (EBCD) based on environmental scan of best practices (Fall 2014)

• Decision to start with oncology services where Lean process improvement processes and pt/family engagement already initiated
Aims

• Test the effectiveness of the EBCD approach as a way of integrating patient, family & staff perspectives in efforts to improve care

• Improve patient, family & staff experience

• Improve the oncology orientation process & support materials to ensure oncology patients, families & staff have the knowledge and resources to become good partners in care
Objectives

• Capture patient experiences through observation, interviews and video (May – June 2014)
• Deepen understanding of the experience through 'feedback events’ (Fall 2014)
• Prioritize issues and recommend solutions for executive team approval and support (November 2014)
• Co-design, implement and measure the impact of smaller unit-based improvement initiatives (January – September 2015)
• Adjust and embed the EBCD approach and/or lessons learned into CHEO standards and practices (Fall 2015)
1. Set up
2. Gather staff experiences
3. Gather patient/family experiences
4. Bring patients and staff together to share experiences & begin co-design
5. Detailed co-design activities
6. Come back together: celebration, review & renewal

Adapted from Bate and Robert (2007)
G. Robert et al. “Patients and staff as codesigners of healthcare services”, *BMJ* 2015;350:g7714 (available at http://www.bmj.com/content/350/bmj.g7714.long).

Although codesign projects typically bring about a series of incremental quality improvements, the partnership between patients and staff often leads to deeper, longer term changes in attitudes and behaviours.
EBCD measures

• Aim 1: Testing EBCD effectiveness
  – Perceived collaboration/partnership
  – Patient/family/staff involvement
  – Increased understanding of experiences
  – Generation of improvement ideas

• Aim 2: Improved “early days” experiences for oncology patients, families and staff
  – Knowledge of roles/responsibilities and where/how to access resources
  – Consistency in messaging
  – Increased feelings of confidence
  – Knowledge and ownership of PFCC behaviours
I felt safe and comfortable during this process, despite touchy/difficult subjects that were highlighted. (Staff)

Great summary of real issues. Hearing it from people (vs written documentation) makes a BIG difference. (Parent)

Great to hear both sides, especially that there is a great deal of commonality. (Parent)

Very excited about future projects that stem from the process. (Staff)
Outcomes

1. **Redesign oncology patient/family orientation process and supporting materials**
2. **Optimize orientation for new staff**
3. **Develop “Know Me” tool**
4. **Revisit use of space and free space for private conversations with families**
5. **Raise awareness of oncology patient/family experiences in the Emergency Department to identify improvement opportunities**

6 staff improvement ideas

8 patient and family improvement ideas
Lessons learned

• Importance of integrating patient and family engagement and quality improvement efforts earlier in process
• Need to tighten timelines and clarify reporting structure
• Better connection/link between patient experience and quality improvement teams
• Current success attributed to EBCD key participants’ ownership and will to implement improvements
# EBCD and Lean integration @ CHEO

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<tr>
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<th>EBCD</th>
<th>Lean</th>
<th>How we bridged the gap?</th>
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<tbody>
<tr>
<td><strong>Origins</strong></td>
<td>UK researchers (2006) in healthcare services</td>
<td>Japanese engineer (1930s) in manufacturing industries</td>
<td>Looked to leaders in the field: ThedaCare and Virginia Mason Medical Center</td>
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<td><strong>Mindset</strong></td>
<td>Abundance of curiosity</td>
<td>Problem-solving</td>
<td>EBCD data used to shed light on underlying problems</td>
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<td><strong>Focus</strong></td>
<td>Patient, family and staff experiences (how did it feel?)</td>
<td>Value-added activity (what did you do – would your customer pay for it?)</td>
<td>“Current state map” of staff process steps juxtaposed with “emotion map” of pt/family experiences</td>
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<td><strong>Process</strong></td>
<td>Pt/families, staff working together as “quality detectives” to bring about change</td>
<td>Plan, Do, Check and Act (PDCA) cycles to identify and eliminate waste</td>
<td>Lean thinking was used to structure EBCD data to inform improvement projects</td>
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What does it take to build true partnerships?

• Think about the purpose & role of the engagement-know what you are looking for, and match & form agreement
• Use many mechanisms from the Engagement Toolkit or Continuum
• Partner=Equals; so know when you want a partnership, an advisor, an opinion, or what exactly??….
• Make sure you really are committed to engagement and be prepared for what you get-voice of the ‘customer’
• Keep it flexible to suit patients and families’ ability to commit and their changing interests over the life of your initiative(s)
• Close the loop back to patients & families, be honest about everything and continue to be courageous
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