From Volumes to Valued Experiences

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Value-based healthcare

Value

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Outcomes that matter to patients and caregivers

Costs throughout the patient journey

Canadian Foundation for Healthcare Improvement (2018)
Measuring Patient and Caregiver Experience as a Critical Component of Performance Measurement

http://www.longwoods.com/publications/healthcarepapers/25405


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3 countries (Italy, UK, Canada)
5 Canadian provinces (BC, Alberta, Manitoba, Ontario, New Brunswick)
Key arguments

**WHAT?** Measure experiences *outside* the healthcare system to provide insight on what needs to change *inside* the healthcare system.

**WHO?** Focusing on patient experience is necessary but insufficient, (family) caregiver insights and experiences require attention.

**WHEN?** Move from ‘one-time, single-sector’ measurement to ongoing iterative measurement across sectors.

**HOW?** Embed measurement within engagement capable environments.
What do we measure/consider?

Considerations

• Social determinants of health (impacts access to health care and outcomes)
• Take an inventory of current measures - what is useful? What is useless?
• Satisfaction does not equal experience

What matters most to patients and caregivers? What are their priorities?

• Patients prioritize independence over staying alive (Fried et al 2011)
• Standardized tools often miss things that matter to people (caregiver information and capacity, priorities, etc.)
Outcomes of importance
Patients and caregivers want to:

- feel heard, appreciated, and comfortable
- have someone they can count on
- understand how to manage health and what to expect
- be as independent as possible
- feel safe
- easily access meaningful health and social care

Kuluski, Peckham, Gill et al, submitted
What does it mean to feel heard?

“...it felt like you’re part of the family, it was really good. This one here is different, you’re just a number.” New Zealand Patient

Activities:

• talks to patient and caregiver like a friend
• doesn’t judge
• focuses on the person outside the diagnosis
• takes their time
• listens intently
• explains why certain things may not be possible and proposes alternatives
Consider trade-offs

• A “win clinically can be a loss personally”  (Glasby 2017)

• Meeting a patient need can come at the expense of caregiver well-being

• Goals of care—between patients, caregivers and providers seldom align  (Kuluski et al 2013)
  • We need opportunities to articulate and negotiate care goals amongst multiple stakeholders.
WHO do we measure?

Don’t forget the caregivers

• Family and friend caregivers often feel excluded from the care team and from relevant discussions

• They are often the ‘common traveling’ record for the patient and hold important *tacit* knowledge

• They also have needs that require attention and support
  • Feel unrecognized in their role
  • Have no breaks even when services are in place
  • Yearn for educational and financial support (Kuluski et al 2018)

• Important not to forget about *care providers* (Quaglietta & Popovich 2017)
  • Measuring joy at work
WHEN do we measure?

• During the care episode/ after the care episode?
  • Opportunity to assess, change, improve during care episode vs. reflecting back (may be subject to recall bias) and may be receiving continuous care and unclear what is being assessed.

• Within sector or cross sectors?
  • We tend to do the former (e.g., Hospital Experience Surveys) reflecting the fragmentation/structure of our health care ‘system’
  • Care transitions experience captured through research
HOW do we advance this?
Creating Engagement Capable Environments

Enlisting and Preparing Patients

Asserting patient centered care and experience as a key goal

Communicating patient experiences to staff

Ensuring leadership support and strategic focus

Engaging Staff to Involve Patients

Supporting teams and removing barriers to engaging patients

Baker et al 2016; Baker & Denis 2011
HOW do we advance this?
Creating Engagement Capable Environments

• Focus on *not only creating but sustaining* engagement capable environments (Estabrooks 2017)

• Consider the role of geriatricians in championing some of this work (McCloskey et al 2017)

• Consider impact on provider workload
  • Trade-off between time taken to collect data and patient care?

• What do we do with the information we collect?
  • Avoid *cynical placation* (Glasby 2017)

• Use mixed methods (to capture needed context)
Learning Health System
Informed by Patient and Caregiver Experiences

The Blue Arrow. How we usually do things. Collect information, analyze it and reflect on what it means.

The Red Arrow. The most important (but neglected part). We need to feed the information back to appropriate stakeholders, try something new and continue to tweak it.

Friedman, 2014

http://www.learninghealthcareproject.org/section/background/learning-healthcare-system
Health Care Workforce

Brave Leaders

“A brave leader is someone who says I see you. I hear you. I don’t have all the answers, but I’m going to keep listening and asking questions.”

Brene Brown (p.195)
The Answer is Not Having the Answer
Just ask more questions

“Have more ‘back stage’ conversations ‘on stage’ with patients and caregivers. It’s ok not to know the answer. Being open about it creates partnerships that have everyone looking for it and goodwill to keep going if the first solution isn't the right one.” Clinical Director

• Being vulnerable together sparks creativity (Brown)

What does this mean for policy?
• Incentivize: embedding research in practice; teamwork and team building
• Reduce waste- how much of our day (clinical activities, data collection, etc.) generate no value for patients, families, providers, us?
In Sum

In order for health care to bring value to patients and their caregivers we need to.....

1. **understand** what is most important to them
2. minimize use of measures that bring no value
3. pay attention to provider needs and experiences (including workloads)
4. measure **overall health** experience **across** sectors
5. invest in **structures** and **processes** that allow **time** to engage authentically and capture things that matter to people including creating a culture for teamwork and trust
6. implement processes to **feedback experience data for performance monitoring and improvement** (allowing us to act on what we measure)
References


References


Wojtak A. Reacting to Patient Experience Results - How Can We Be Proactive? Healthc Pap 2017;17:34-9.

Acknowledgements