

From Volumes to Valued Experiences

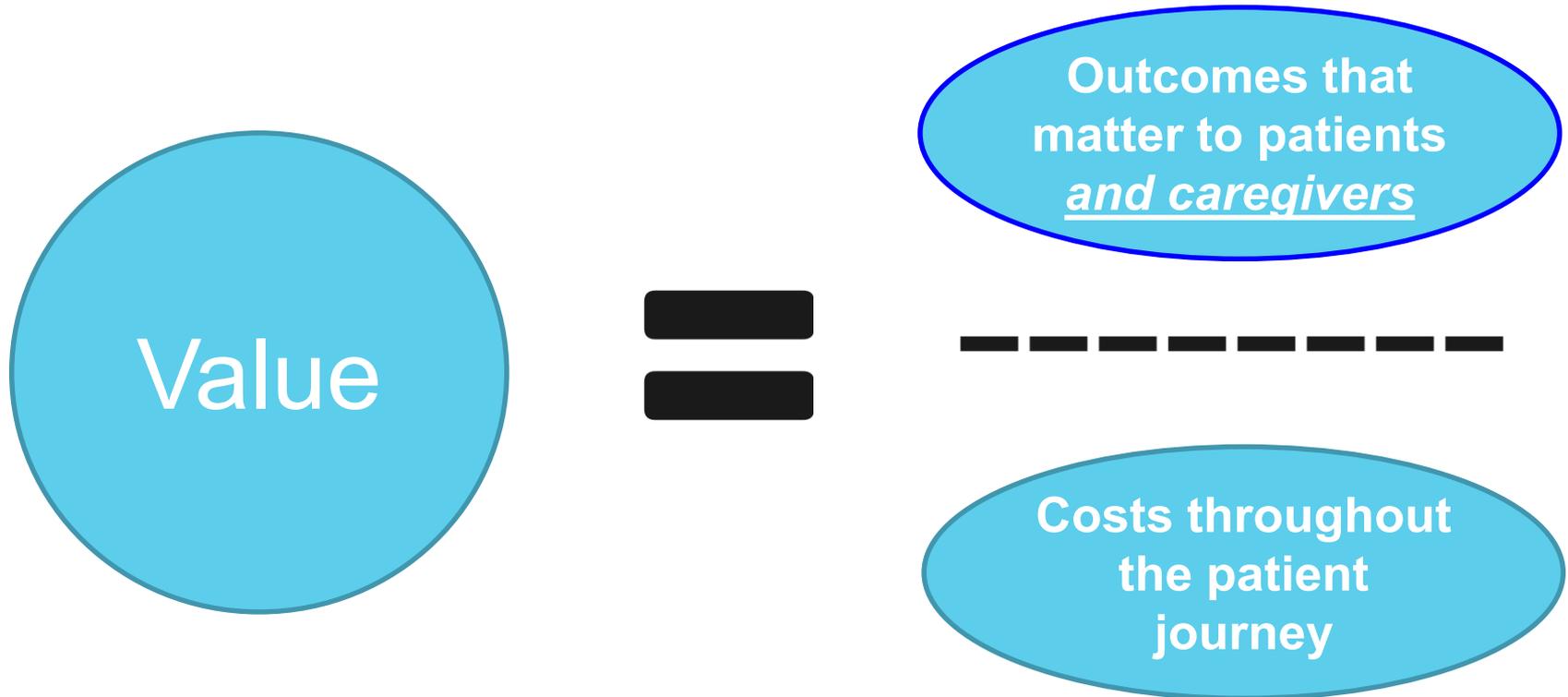
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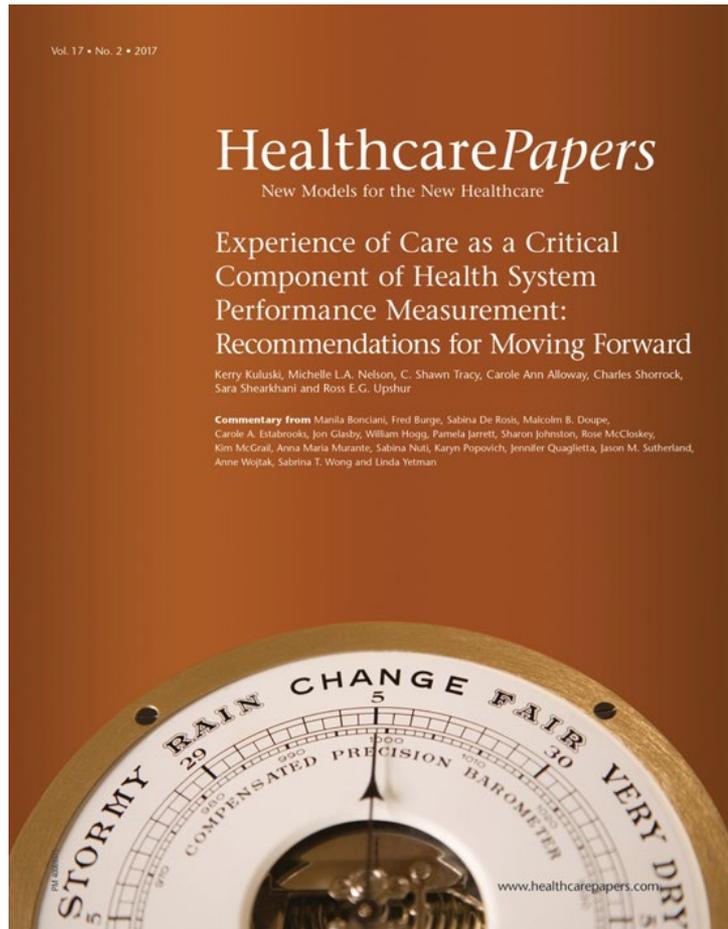
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Value-based healthcare



Measuring Patient and Caregiver Experience as a Critical Component of Performance Measurement



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

Kuluski, K., M. L. A. Nelson, C. S. Tracy, C. A. Alloway, C. Shorrock, S. Shearkhani and R. E. G. Upshur (2017). "Experience of Care as a Critical Component of Health System Performance Measurement: Recommendations for Moving Forward." *Healthc Pap* 17(2): 8-20.

Editor in Chief: Dr. Steini Brown

Guest Editor: Dr. Jason Sutherland

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

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

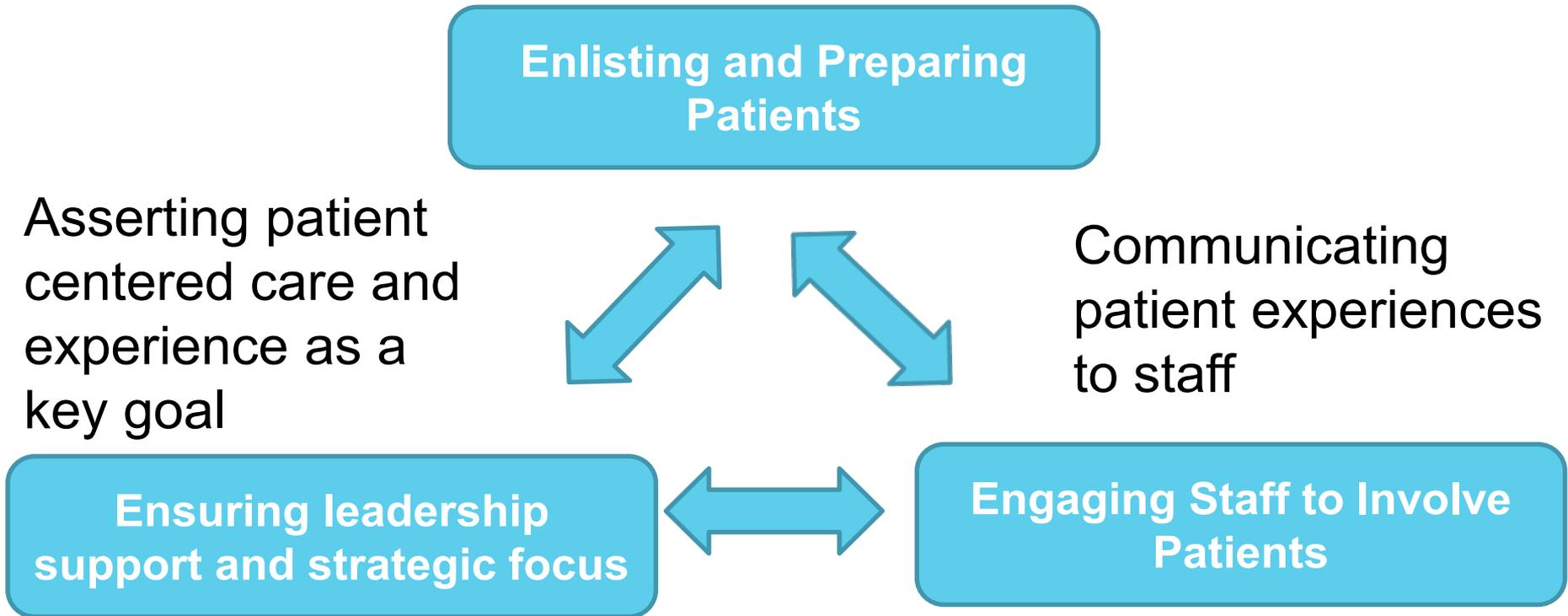
- Family and friend caregivers often feel excluded from the care team and from relevant discussions
- They are often the 'common traveling' record for the patient and hold important ***tacit*** knowledge
- They also have needs that require attention and support
 - Feel unrecognized in their role
 - Have 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)

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



Supporting teams and removing barriers to engaging patients

HOW do we advance this?

Creating Engagement Capable Environments

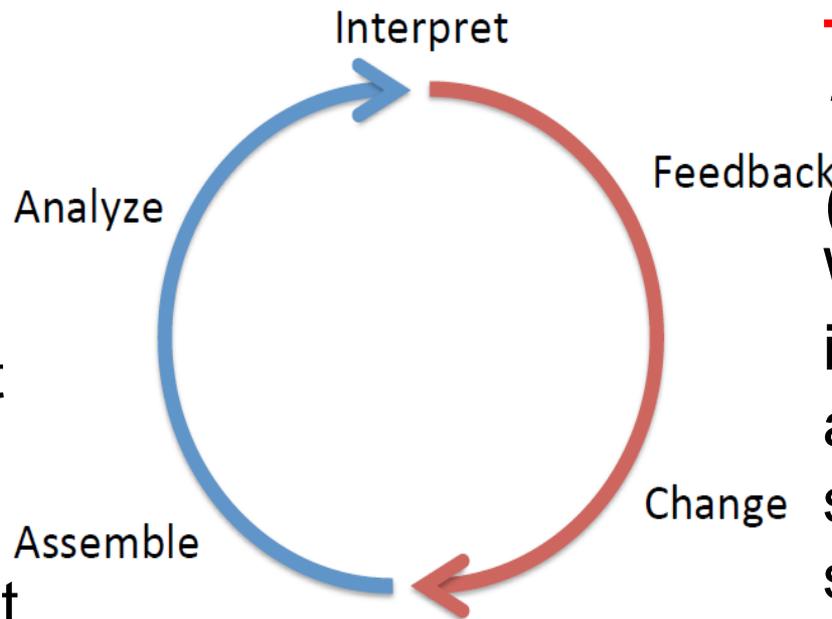
- Focus on *not only creating* but *sustaining* engagement capable environments (Estabrooks 2017)
- Consider the role of geriatricians in championing some of this work (McCloskey et al 2017)
- Consider impact on provider workload
 - Trade-off between time taken to collect data and patient care?
- What 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.

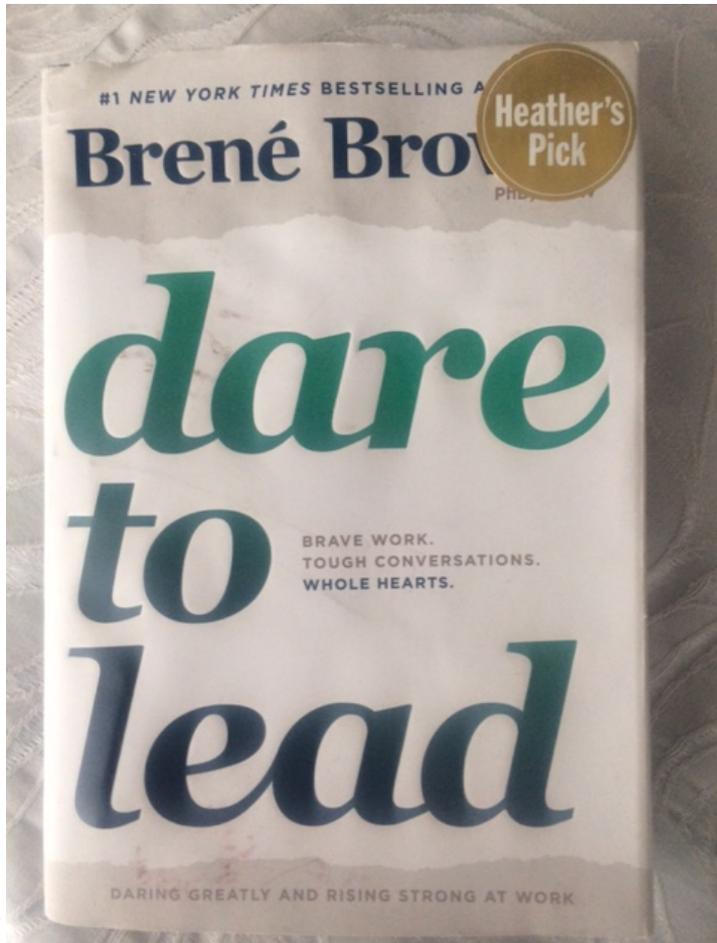
The most important (but neglected part). We need to feed the information back to appropriate stakeholders, try something new and continue to tweak it)

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)

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