

From Volumes to Valued Experiences: Measurement and the Challenge before Us



THE AUTHORS RESPOND

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ABSTRACT

We are grateful for the thoughtful discussion and ideas put forth in this issue on the measurement of healthcare experiences. Our colleagues, who span multiple jurisdictions across Canada and internationally, agree that we need to do a better job at engaging patients and families in their care and measuring their experiences across health services and sectors. In this response paper, we reflect on three core content areas that were identified across the eight papers in this issue: the role of context and engagement-capable environments; approaches to improve the measurement of experience and acting on results; and challenges that must be attended to in our quest to make our healthcare systems work better.

WE THANK OUR colleagues who contributed to this issue on performance measurement and experiences of care. They shared important insights on how to capture care experiences in a meaningful way to support quality improvement throughout the healthcare system. Moving this agenda forward is no small feat but is required for healthcare systems to work better for patients, their

caregivers, providers, directors, policy planners and researchers.

In the lead paper (Kuluski et al. 2017), we made four key recommendations: measuring experiences beyond the healthcare system, including the experience of unpaid (often family) caregivers, measuring experience across sectors and building engagement-capable environments. Our

respondents, who spanned multiple jurisdictions across Canada (British Columbia, Alberta, Manitoba, Ontario and New Brunswick) and internationally (UK and Italy), agreed with our recommendations and pushed forward some key ideas. For example, additional insight into the role of context and engagement-capable environments was provided. Contributors shared approaches to improve the measurement of experience (one which has been implemented and sustained). Finally, a number of cautions and challenges that need to be addressed before moving forward were shared. It is from these three anchors – context, approaches and challenges – that we structure our response.

Attending to (Engagement-Capable) Context

Contributions by Estabrooks (2017) and Doupe (2017) emphasized the importance of context, particularly attending to (and learning from) environments that provide capacity for patient and caregiver engagement. Doupe stressed that measuring experience only offers a partial reform solution. Figuring out how to effectively engage people as partners in their care is important in and of itself and should be measured for its effectiveness in achieving desired outcomes. He also suggested that engaged patients and caregivers can alert us when efforts to create more “efficient systems” trade off with a quality experience for patients and families. We agree with the caveat that we need to be mindful of WHO is being engaged among patients and caregivers. Being conscious of engagement barriers for patients and caregivers (lack of time, resources) and/or individual beliefs about type and level of engagement (Nelson et al. 2014) mean that the voices of patients and caregivers may represent only a subset of the broader whole. Creative ways to engage with

various types of patients and caregivers to inform system change is required.

Estabrooks (2017) emphasized the challenge of not only creating but also sustaining engagement-capable environments. She highlighted that any change in a system, whether it’s new forms of measurement, new programs, process changes or others, can and should be informed by existing theories and frameworks such as complex adaptive systems theory and others. These theories point to key attributes that influence implementation including (and not limited to): leadership approach, organizational culture, trusting relationships, willingness to learn, compatibility of what’s being proposed to existing systems, level of complexity of the proposed activity, etc., which all need closer attention as we seek to influence measurement processes in our healthcare system.

The discussion of context reminded us that healthcare systems and their various components are examples of “complex adaptive systems” (McDaniel et al. 2013) – comprising many components, and agents, which behave and evolve, in mostly unpredictable ways. These agents are shaped and bound by broader contexts. In healthcare, when attempting any type of reform we constantly hit up against the historical institutions that have hardwired the system into a reactive, siloed, mostly acute care-focused, “provider knows best” model. Our measurement systems and approaches, as highlighted by Wojtak (2017), mirror this very structure.

As Glasby (2017) pointed out, each sector of our healthcare system has its own incentives, goals, metrics and governance structures. While a person’s experience in one sector or organization may be great, the overall experience across the health system and transitions between settings may be dreadful. Understanding the activities within sectors is important, but also required is an understanding of experience across sectors, and all

contributors highlighted that this is a gap that needs to be addressed. Our co-author and a caregiver, Alloway, reminds us that at the end of the day those complicated structural pieces (the machinery that shapes the various sectors and silos of the “system”) are less relevant to the user. What matters is the overall care experience and how people feel as they interact with various providers involved in their care.

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Approaches

We were delighted to learn about the performance measurement system that has been successfully implemented by our Italian contributors (Nuti et al. 2017). Since 2004, Tuscany (later to be joined by 12 other regions) has implemented a performance measurement system that enables them to measure an entire clinical pathway of specific patient groups (including maternal care, chronic care, oncology, among others). By linking administrative data to patient experience surveys they are able to capture patient outcomes, including experience, within and between sectors, as well as the overall care journey. Providers in each sector can view their own performance as well as that of their peers. Policy planners can get a systems’ view of experience to inform policy priorities and planning. While mapping out a pathway for people with multiple co-morbidities and social care needs may be less straightforward than the examples shared by Nuti et al. (2017), her example demonstrates that cross-sectoral performance measurement structures are not only possible but can be scaled up and spread to other jurisdictions. This Italian example addresses Wojtak’s (2017) concern that, in focusing on cross-sectoral measurement, we would minimize

a focus on “within sector” measurement, as Nuti et al. (2017) suggest that we can do both.

An example, closer to home, shared by our Ontario contributor Wojtak (2017), highlighted what measuring and acting on patient experience data entails. The former Ontario home care organizations (Community Care Access Centres [CCACs]), now embedded within the province’s health authorities/Local Health Integration Networks is the first sector in Ontario to measure an experience systematically across the province, as all CCACs at the time participated. We were inspired by the concerted action taken to change practice when it was found that care experiences in the Toronto Central region were lagging behind its peers. The most important factor in shaping experience, communication, was addressed head-on through their Changing the Conversation initiative, which yielded positive results regarding patient care and experience.

Cautions and Challenges

The contributors shared a number of cautions and challenges, which must be addressed as we move to more meaningful measurement of patient and caregiver experience.

First, Nuti et al. (2017) described how the concept of value in healthcare is changing – from volumes (numbers of procedures, throughputs, etc.) to meaningful experiences of people; however, adopting this into performance measurement systems is challenging. Perhaps this is why we see promising examples as “one offs” as opposed to spread initiatives. McCloskey et al. (2017) noted that geriatric medicine, which transcends silos, engages multiple disciplines and involves families, is well positioned to lead a more systematic effort in experience measurement. We add that primary care, and perhaps more integrated models of community-based primary healthcare, are also a natural platform from which to lead these efforts.

Second, if we add any new measures and approaches to better understand system performance, we need to be mindful (as Doupe [2017] cautions) not to overcomplicate the vast number of measures we already have. Keeping what works well (including traditional measures that capture cost, adverse events, etc.), adding new measures and figuring out which ones can be replaced will require some dedicated reflection.

Third, our contributors stressed that providers cannot be left out of the equation. Responses led by McCloskey et al. (2017), Quaglietta and Popovich (2017), and Wong et al. (2017) reminded us that we need to be mindful of the impact of measurement expectations on provider workflows, capacity and patient care. This necessarily raises the question of who would do the measuring and how this could be embedded most fluidly into existing practices. If providers are expected to measure experiences in new and different ways, what is the value added? Will it take time away from other essential clinical activities? We don't doubt that clinicians and care providers want patients and families to have a better care experience, but they may view "more data" as a distraction from providing good patient care. Wong et al. suggested that practice supports are required (such as an assigned role in primary care) to collect, analyze and feed data back to the practice with sufficient time to reflect and act on the results, without adding to a provider's workload. Practice facilitators are an emerging role that can support such quality improvement efforts more seamlessly (Taylor et al. 2013). Some upfront investment from professional associations, provincial quality organizations or ministries of health is required. She also suggested leveraging existing technologies such as software embedded in Electronic Medical Records to administer targeted data capture of patient experience through automated processes.

Measuring the experience of providers was also recommended by Quaglietta and Popovich

(2017). They pointed to emerging research that suggests measuring factors such as joy at work among providers and workplace culture are key elements that will influence and shape the overall patient and family caregiver experience.

Fourth, a few of our contributors pointed to the different sets of priorities and needs that various stakeholders bring to the table. In our previous research, we too see the differing priorities and goals described by patients, their caregivers and care providers (Kuluski et al. 2013). Aligned with Glasby's (2017) commentary, our previous study found that a "win" clinically may be a loss personally, so we need to design "space" within our system so that key stakeholders (e.g., patients, caregivers and providers) can have important discussions about their care, put themselves in the shoes of the other and negotiate a plan going forward (Kuluski et al. 2013). Through these conversations, stakeholders will naturally hit on the "non-healthcare things" (lifestyles, goals, priorities) that need to be understood and acknowledged to address the "healthcare things" (e.g., medication and treatment regimens, etc.) (Jethwani and Sperber 2017).

Perhaps our greatest challenge in this measurement agenda is that we are trying to systematize something that is inherently individual. There is continuous tension around formalizing, "check boxing" and standardizing to achieve consistency and comparability – but there is no science in particulars, as each person and their experience is unique. Our respondents argue for the importance of going both broad and deep. Broad by way of a larger, population-level snapshot for standardized reporting for the purposes of benchmarking and comparability; and deep by way of qualitative approaches of a smaller subset of people (including culturally and linguistically diverse populations, heavy and non-users of healthcare), to inform targeted responses. All contributors agreed that while time intensive, getting the additional context that a qualitative

approach allows, whether it be at the bedside, as suggested by Quaglietta and Popovich (2017), or from external stakeholders, as done by the CCACs in Wojtak's (2017) example, will provide a more fulsome "story" to guide quality improvement efforts. Such approaches are needed to assess how current practices or new interventions are working, what makes them work and what needs to change.

To that end, measuring without action is dangerous, and perhaps the biggest caution put forward by our contributors. Collection without action leads to, in Glasby's (2017) terms, clinical placation – making people feel as if their viewpoints and experience matter with no likelihood that anything will result from the sharing of this information. This is certainly an expressed concern among applied researchers who may interview patients and caregivers about their experiences to then be faced with the questions: What will you do with the results? What difference will it make?

Provincial or federal oversight is needed to standardize data collection of care experiences for purposes of broader system planning and comparability. The Canadian Institutes of Health Information, provincial governments, quality improvement organizations and professional regulatory bodies were the obvious sources to lead this effort. McCloskey et al. (2017) noted that stable funding is needed so that work to date, which is often short term and done in isolation, can be replaced with a systematic, cross provincial (or cross Canada) approach. We see some examples at a policy level to standardize data capture across a province – including British Columbia's Satisfaction Steering Committee which is mandated by the provincial government to standardize definitions, data collection and minimize provider burden. While a step in the right direction, the approach remains sector specific (acute and long-term care) and primary care has been excluded to date. In Ontario, Health Quality

Ontario is embarking on a patient experience measurement strategy and we hope this dedicated issue will inform their activities.

Glasby (2017) posed a provocative question – why measure experience at all? Perhaps if we assume that patients and caregivers are experts in their own care we can just grant patients and families greater choice and control in their daily activities (including the selection of service providers and resources), with the goal of helping them live more meaningful lives. In doing so we may accomplish a truly healthy system for all. He made note of the UK's personalization agenda (personal budgets for patients and their families) which is akin to Ontario's plan to integrate this model within its homecare program (as part of the Patients First Action Plan). This approach is innovative and may work for some patients but may widen the chasm between resourced patients and those who cannot drive their own care.

Finally, on the provider side, we work in a system that values and incentivizes "curing, fixing and expediting care." This "one and done" approach may work well (or even be preferred) by people with acute and episodic conditions who wish to enter and exit the healthcare system relatively quickly and get on with their lives. On the other hand, people who require continuous care for ongoing complex care needs may be seeking relationship-based care (Leppin et al. 2015) and the time to discuss their priorities and values as it goes hand in hand with managing their conditions (Richards et al. 2015). For this latter group, the experience in the system, and its measurement, may hold greater value. It has been suggested that a paradigm shift is required (Richards et al. 2015), characterized by a reorientation of training, organizational and practice incentives to promote (and allow time for) holistic approaches to care (Yardley et al. 2015). In doing so, perhaps we reach a point where person-centred care is a given and we don't need to measure experience at all.

Since we are some time away from this sort of “utopia” we encourage policy planners and quality improvement organizations, who are embarking on the performance measurement journey to consider our recommendations as they start to move the dial towards a system that both values patient and caregiver input and is equipped to respond.

Acknowledgements

We extend our sincerest gratitude to Dr. Adalsteinn Brown, Editor-in-Chief for *Healthcare Papers* for providing us with the opportunity to lead a journal issue on this important topic. Dr. Jason Sutherland was a huge support as guest editor and helped us frame our arguments as effectively as possible. We appreciate the support from Dianne Foster-Kent, Editorial Director at Longwoods Publishing Corporation, for her ongoing encouragement and patience as we put this issue together. Most of all, we thank the commentary authors for their time, insight and dedication to this issue by offering invaluable perspectives and recommendations for moving forward.

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