Redefining Health Care

A DIALOGUE ON HEALTH POLICY

Patient- and Family-Centred Care: Focus on Transitions

OHA ONTARIO HOSPITAL ASSOCIATION

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Questions? Comments?
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Focusing on Patient-and Family-Centred Care to Improve Transitions

The Ontario Hospital Association (OHA) is committed to being a leading contributor in the health policy dialogue by sharing and generating ideas to improve the province's health care system. As part of this effort, *Redefining Health Care* was launched in 2016. Since then, the journal has focused on core issues that are pivotal to the health system transformation underway in Ontario, including health system reconfiguration and hospital-physician alignment. In this issue, the dialogue centres on patient- and family-centred care, within the context of patient care transitions.

As patients navigate the bridge between two points of care or two different providers, they are at risk for gaps in communication and care. These gaps can lead to adverse events, such as readmission and sub-optimal care outcomes. As a system, that's what we have found; and more importantly, it's what we've been hearing from patients.

Patients have identified care transitions as an area where they continue to struggle due in part to lack of available supports and collaboration by providers.

Ours is a system that is still in transition from a characteristically disjointed model, to one that is better integrated and can offer a more seamless health care journey to patients and their families. However, in order to get to our goal, system leaders, health care providers, government and policy makers, have recognized that the involvement of patients and their caregivers is essential. We require the input, guidance and participation of patients and their caregivers to understand where the gaps are, gauge progress, and ultimately, for long-lasting change to occur.

This issue features a host of perspectives, including those of patients and caregivers, as well as strategies to improve how we capture and measure the patient and caregiver voice, and ideas about how we can effectively spread successful initiatives.

Undoubtedly, this is a complex and challenging undertaking, but a necessary one.

As hospitals evolve beyond their traditional role, and the aim of seamless care across the continuum becomes a top priority for the system, patients and caregivers must become equal partners in contributing to system improvement. This means attaining better outcomes, safer care and a more positive patient and caregiver experience.

I sincerely hope you enjoy reading this issue and continue to engage with peers, patients and caregivers in important discussions such as these, that will help drive the system forward.

Jamie McCracken signature

Jamie McCracken
Board Chair
Ontario Hospital Association

The Patient Journey Knows No Boundaries

Our health care system has been designed with the care provider and the institution as the starting point, rather than beginning with the needs of patients and their families. This traditional approach has led to a fragmented system, with invisible walls between services and organizations that often act as significant barriers to patient- and family-centred, seamless care.

The urgent need to improve is best illustrated by the personal journeys of patients and their loved ones during their intimate interactions with the health care system.

After years as a hospital CEO, I took such a journey and it has changed my life. For two-and-a-half years, I helped my husband Bill navigate his way through the system while he valiantly battled cancer. With one CT scan, our lives changed forever. He was diagnosed with an advanced stage of cancer and we had to re-set our life priorities very quickly. It was overwhelming news, and what followed was a very stressful and gut-wrenching experience.

Despite my background as a nurse and my experience as a leader and hospital CEO, I was not fully prepared for the emotional rollercoaster that came after Bill's initial diagnosis. Together, we had no choice but to become health care navigators overnight for two separate systems: the hospital system and the home care system. They were two different worlds.

There were profound disconnects in Bill's care and in our relationships with those who were providing it. This became very clear when we found ourselves repeatedly updating a series of home care nurses about our latest experience in hospital or vice-versa. We were overjoyed if the same home care nurse was assigned to us more than once, because this meant we did not have to recount our entire story yet again.

I know that the care providers both in hospital and in home care were well-intentioned, but they were hobbled by institutional structures, which are reinforced by differing organizational cultures, rules, paperwork and legislation.

Living through a critical illness is tough enough without the additional challenges experienced as the patient goes back and forth across silos of care. Examples include inconsistency in procedures, varying levels of quality and safety, incomplete information, gaps in communication and multiple caregivers not connected to each other.

My husband's journey led to a clear understanding about the absolute importance of, and need for "patient care without borders."

Providers need to close the gaps that exist between silos and design one continuous, seamless and integrated system of care so that patients and their families do not experience the trauma of needless, frustrating "boundaries" as they
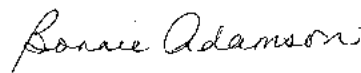
move between and among various agencies. For us, it made a tremendous difference when continuity was present – it made our ability to continue, both physically and emotionally, more bearable. When it was lacking, it made an already difficult experience even worse.

What stood out the most for me through this journey is that any meaningful and fundamental change must begin with leadership and culture.

I strongly believe that consistent, authentic, compassionate, people-centred leadership will create cultures of empathy, learning, engagement, and empowerment where patient- and family-centred care will thrive. The hallmark of such leadership is being humble enough to listen, learn, empathize, and equally important, to partner with patients and their families in order to understand their unique needs at their great time of need.

There is a wonderful and welcomed awakening within the system about the importance of listening to the voices of patients and their families, where their input matters. It is taking place from the boardroom to the bedside, and is clearly articulated in the government's *Patients First* strategy.

Collectively, courageous system leaders have been given a profound opportunity to drive real change. I encourage our leaders to put patient and family experience at the heart of their leadership. Patients and their loved ones deserve nothing less.

Bonnie Adamson

Bonnie Adamson
Supervisor
Brant Community Healthcare System
Former hospital CEO

Patient Experience Surveys

The Ontario Hospital Association's aim is for Ontario's hospitals to be equipped with appropriate and effective patient experience measurement resources that enable them to better understand and improve the experience of their patients.

With guidance from the sector, the OHA has been leading ongoing efforts to refresh and enhance the patient experience surveying instruments available to hospitals in the following categories:

- Acute Adult Inpatient
- Emergency Department
- Maternity Inpatient
- Mental Health and Addictions
- Pediatric Inpatient
- Rehabilitation Inpatient
- ✳ NEW – Day Surgery
- ✳ NEW – Outpatient Specialty Clinics

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Building Bridges:

Measuring Continuity Across Care Transitions

By: Lina Neves-Mera and Anthony Jonker

Currently, there are no existing, validated tools in Ontario, Canada or abroad that effectively measure continuity of care across the full care continuum.

Patients in Ontario consistently experience less than favourable transitions as they move across care settings (HQO, 2015). Problematic transitions can occur from and to every type of health care setting, and have been correlated with adverse events, higher readmission rates and increased costs (Forster, Murff, Peterson, Gandhi & Bates, 2005).

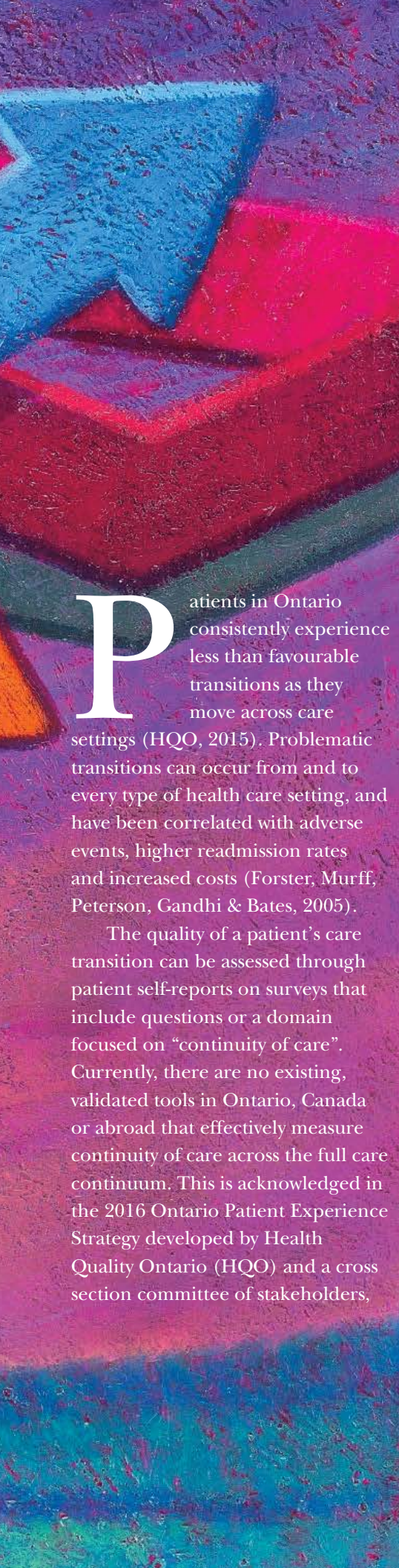The quality of a patient's care transition can be assessed through patient self-reports on surveys that include questions or a domain focused on "continuity of care". Currently, there are no existing, validated tools in Ontario, Canada or abroad that effectively measure continuity of care across the full care continuum. This is acknowledged in the 2016 Ontario Patient Experience Strategy developed by Health Quality Ontario (HQO) and a cross section committee of stakeholders,

which includes the Ontario Hospital Association (OHA) (HQO, 2016). However, to the extent that we do measure patient experience around transition planning and management, data from the Canadian Patient Experience-Inpatient Care (CPES-IC) survey in Ontario show that experience in this domain is moderately correlated with overall patient experience (OHA, 2017). As such, if experience scores in some aspects of continuity (informational, managerial and/or relational) improve, we should expect to see some modest improvements in overall patient experience scores.

In an effort to stimulate discussion on options for Ontario, this article conceptualizes a few reasons why this is a worthwhile endeavour, and discusses ways of measuring continuity of care.

Why Measure Continuity of Care?

Measuring continuity of care allows patients to share their care transition experiences in more detail. This information allows health care providers and system leaders to more accurately identify problems with care transitions and evaluate interventions or policy changes aimed at improving continuity and meeting patients' expectations. Finally, it enhances strategic decision-making, and the management and monitoring of how the different parts of the system are working together. Without effectively and systematically measuring the experience of patients across transitions in care, it is difficult to know how these experiences impact overall experience and other metrics, such as patient safety associated with medication adherence, readmissions, etc. In addition, these metrics can be trended over time at the population level, to pinpoint specific opportunities to improve transitions across care settings.

Transition success is not determined at a single moment in time. A tool that measures continuity of care may tell us how patients experience care "on the bridge" as they cross from one health care setting or provider ("the sender") to another ("the receiver"). To be truly actionable, the survey results would have to be made available to those involved in the transfer of care, on both ends of the bridge, so that they

Transition success is not determined at a single moment in time.

Continuity of Care Defined:

Continuity is the degree to which a patient experiences a number of discrete health care events as coherent, connected and consistent with their medical needs and personal context. Three types of continuity exist in all care settings:

- *"Informational continuity*—The use of information on past events and personal circumstances to make current care appropriate for each individual"

- *"Management continuity*—A consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs"

- *"Relational continuity*—An ongoing therapeutic relationship between a patient and one or more providers"

(Haggerty, Reid, Freeman, Starfield, Adair & McKendry, 2003)

could "see" themselves in the data and use the data to guide improvement strategies for care transitions.

Current State

The OHA has helped hospitals measure patient experience for the past two decades. Many health care providers and organizations are using longitudinal, post-discharge surveys that provide rich information on a number of domains that make up the patient experience. These surveys focus on particular hospital care settings, conditions, or patient populations. For example, the Ontario Emergency Department Patient Experience of Care Survey and the CPES-IC are tools that measure the patient experience for emergency department and inpatient hospital care, respectively.

Other patient experience surveys are used for similar purposes in other sectors, such as primary care, mental health and long-term care. While many existing sector-specific surveys have standardized questions related to continuity of care, the questions do not capture sufficient information in this area. For example, the questions in the CPES-IC related to continuity of care are specific to activities within the hospital and prior to discharge, but do not address elements of continuity after the patient leaves the hospital. As such, the hospital "senders" are left in the dark about the experiences of their patients once they leave their facilities. Furthermore, patient experience results are not shared with "receivers", which makes it difficult

for parties on either side of the bridge to use the data together to hone in on problem areas and focused opportunities for improvement.

Some of the challenges in measuring continuity of care and sharing the results with "senders" and "receivers" could be addressed if patients transitioned across a more integrated system. Ontario has started to explore this through the integrated funding model (IFM) pilots, a model of care that breaks down the silos by bundling care across different sectors. Because services within care bundles are defined, providers on both ends of the bridge are more easily identified and connected than in non-integrated care models. This care model has the potential to create a more seamless

transition experience for patients and caregivers, and enables one lead organization to take responsibility for experience measurement. Because of this shared accountability among all care providers involved, this approach encourages "senders" and "receivers" to come together to use the data as a catalyst to improve patient experience.

Conceptualizing a Tool for Ontario

Notwithstanding the potential offered by bundled care models, Ontario continues to be a largely siloed health delivery system where measurement of continuity across different health sectors is poor. In an effort to encourage the measurement of continuity of care, three conceptual approaches could be considered for today's environment.

1. **Sector-Specific Surveys**
   The first approach would be to use sector-specific surveys as a vehicle to better understand continuity of care across settings. This would involve supplementing the existing surveys to better capture continuity. British Columbia's *Patient Reported Experience Measures Steering Committee* has developed a module, *continuity across care transitions*, which is appended to existing in-patient experience surveys to better measure the continuity experience of patients upon discharge from hospital.

Adding questions to sector-specific surveys, however, has its barriers. Survey space is at a premium and in an effort to keep length and costs down, this means only a few questions can be added, possibly at the cost of removing existing questions. Moreover, there are no available mechanisms to identify or share experience results with others sharing in responsibilities of patients..

Given the length of current surveys, it may not be possible to comprehensively measure continuity of care or to obtain the level of granularity required for actionable improvement at the ground level. The best one could hope for is a better understanding of patients' experience with the activities that occurred in a specific sector. However, to be able to identify improvement opportunities for patients across care settings, there would need to be questions related to both sending and receiving health care providers as well as a way to identify and share results with those providers.

One more consideration is that some sector surveys (e.g., hospital) are designed to seek patient responses as soon as 48 hours after the patient encounter ends. Patients do not fully experience many aspects of a transition plan within 48 hours following an encounter. As such, patients may not feel as though they can provide comprehensive feedback about their transition experiences when their opinions may only be partly formed or not yet crystallized.

Despite the challenges with this approach, it would nonetheless provide a pragmatic, short-term solution to the paucity of data about continuity of care that currently exists.

2. **General Continuity of Care Survey**
   Developing a new survey specifically designed to measure continuity of care would enable the multidimensional aspects of the concept, as identified by Haggerty et al. (2003), to be measured comprehensively (i.e., information, managerial, relational continuity). The development of the survey would be done in collaboration with stakeholders on "both sides of the bridge", including patient and caregiver advisors.

The survey questions could seek to cover all patient populations regardless of disease or care setting. It would address movement across the health care system as a whole, from the perspective of the patient, and would include questions that address the patient's continuity experience with their general practitioner, specialists, therapists, and home care supports.

At its best, it would identify the care settings in order to allow the patient to be directed to questions in the survey appropriate to that type of transition. This approach should be designed to enable the sharing of results with health care teams who are directly involved in patients' transitions. With this

level of granularity, health care teams in each setting would be able to "see themselves" in the data and because questions would be designed to be actionable, it would be easier to identify what needs to change.

Some may suggest that a survey that covers all patient populations and addresses care across the health system as a whole would be too broad. Instead, some may propose the development of multiple surveys, one for every transition type (e.g., the transition from hospital to home, or from home to long-term care). The reality is, however, people do not move across the system in a linear fashion. Moreover, as patients live longer with complex and chronic illnesses, some may feel that their transitions between care providers and settings do not really "start" and "end".

Developing and operationalizing a survey generic enough to cover all patient populations across all types of transitions would be complicated. For example, who would be responsible for identifying the patients to survey, administering the survey and disseminating the results to the "senders" and the "receivers"? This becomes especially complex when multiple providers are involved on both sides of the bridge. The nature of Ontario's fragmented health system makes these operational factors particularly challenging.

3. **A Hybrid Model**

The third option presents a hybrid of the previous two models that goes further than the first, and while less comprehensive than a general continuity survey, may be more readily achievable. It focuses on the experience of patients who have transitioned between hospitals and other care settings, whether to another facility or to the community. There are many important transitions that are not covered in this model, as this model compromises breadth in favour of relative simplicity.

In this continuity of care surveying model, hospitals would identify patients that have transitioned out of hospital along with information about the specific care setting to which they transitioned (e.g., home, specific rehabilitation centre, specific long-term care home, etc.). A random sample of patients would be sent a general continuity of care survey applicable to all transition types. However, a module specific to their transition route would be appended to the general survey. This module would ask a few short questions about the patient's experience transitioning across care settings and would enable the identification of the providers and organizations involved. For example, a person discharged with a plan to receive home care would receive an additional short set of questions relating to the experiences of care continuity between hospital and

their home setting. By linking the survey results to the specific organizations that served that patient, the results could be shared with both sides of the bridge which is a significant enhancement over current practice. This is one of the major benefits of this model as it would provide a level of specificity that care providers and administrators across the health care system could leverage for actionable improvements along with rich aggregate data to broadly track performance.

Although this model is not universal, it could be argued that it is an important place to begin improving the measurement of continuity given that hospital care, unlike other care settings, is always intended to be transitional. It is also known that a large volume of concerns from patients and caregivers about public hospitals is related to experiences with discharge, as evidenced in the Patient Ombudsman's Annual Report (2017).

Real-Time Measurement in Parallel

Real-time or near real-time measurement occurs at the moment of or shortly after care delivery. It allows patients the opportunity to provide immediate feedback about their experiences and is oftentimes used by health care providers to drive quality

If a new approach is considered, it will be important that this tool captures the multidimensional aspects of continuity of care and reaches further than activities in one sector.

More importantly still, throughout the process of designing a solution to measure continuity of care in Ontario and in order to share data across providers, patients, caregivers and providers must all be engaged to ensure that the approach reflects their perspectives and experiences.

improvement by seeking to benefit from its rapid-cycle nature. However, transitions are not a moment in time; they are broad, complex, non-linear and for some complex patients, they are perpetual.

Applying the value of real-time to this problem requires a different approach to patient experience measurement. Consider the idea of surveying patients more frequently, but with only a few questions specific to their position on the transition bridge. For example, this may include at the bedside prior to being discharged from hospital, 24-hours after arriving at home, and a few days after being home. The advantage of real-time measurement is that it can provide immediate information about the patient's experience that could be used to alert care providers on both sides of the bridge and for service recovery – or taking immediate action to respond to patients when they have less than positive experiences. Over time, patterns of deficiencies in continuity of care could be extracted to inform quality improvement opportunities, drive accountability, measure how different parts of the system are working together and improve the patient experience.

An important consideration is that service recovery can only happen when patient feedback is not anonymous. Without anonymity, there is a risk that patients may be reluctant to be honest with their responses when experiences were less than positive. This is one of the reasons why anonymized, post-discharge measure tools will continue to be important to reduce bias and promote honest reflections on the experience.

Final Thoughts

Like many other jurisdictions, Ontario currently does not capture the lived experiences of patients as they move across care settings. If a new approach is considered, it will be important that this tool captures the multidimensional aspects of continuity of care and reaches further than activities in one sector.

It will also be important to consider an approach that enables sharing of results with the providers and organizations involved during transitions in care, so that the data can be used to improve care for patients.

Lina Neves-Mera is Consultant, Health Policy Issues and Anthony Jonker is Director of Innovation and Data Analytics for the Ontario Hospital Association.

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Through the Eyes of Patients and Caregivers: Anita Manley

Redefining Health Care spoke to a number of former patients and caregivers to ask for their view about care transitions.

Anita is a mental health advocate, advisor and peer facilitator. At The Royal, she volunteers as a peer supporter for the Women's Mental Health Program, was a member of the Client Advisory Council for five years, and former Editor of The Client's Voice Newsletter. Anita represents The Royal as a patient advisor for the Resource Development Advisory Group at Health Quality Ontario and is Co-Chair of the Champlain Local Health Integration Network (LHIN) Patient and Family Advisory Committee (PFAC). Previously, Anita was a Co-Chair of the Champlain Peer Network, The Ottawa Hospital Mental Health Community Advisory Committee and a Board Member of The Canadian Mental Health Association - Ottawa Branch. Anita's special accomplishments include being a recipient of The Royal's 2015 Inspiration Award and a proud mom of two grown daughters.

1. Can you describe an experience when you transitioned from one health care setting to another?

The transition from The Royal's Recovery Unit to home was a big one for me. I had been homeless for almost three years prior to my seven-month hospitalization. Moving into my own place with my own bed seemed like a dream, but it had its challenges as well. I had not managed a budget nor had I been shopping for groceries for years.

My first task was to completely furnish my apartment on a tight budget. I accomplished this task on budget and had everything moved in before discharge. The hospital gave me the time I needed to set up my apartment; they didn't rush my transition at all. I had help from a friend I had met in the hospital, my daughter and support workers from the community. I also went grocery shopping, feeling very anxious. What should I buy? How much will it cost? Over time, my anxiety lessened.

I was discharged from The Royal to the care of the Assertive Community Treatment Team (ACTT). They were like a hospital on wheels. The team that cared for me included a recreational therapist, a nurse, a social worker, a peer support worker and, of course, a psychiatrist. This team was instrumental in supporting my transition. I met with someone on the team in the community weekly. I really felt like they were my friends. I could talk to them about anything. Following my discharge from the hospital, I also had some medical appointments that caused me to feel quite anxious.

The ACTT supported me throughout all my medical appointments. They drove me to appointments and held my hand throughout the whole process. I found this to be very helpful for my recovery

and transition as I had lost all my friends due to symptoms of my mental illness and homelessness.

2. Can you reflect on how your transition impacted you and/or your caregiver?

I would meet with my psychiatrist about once every two months, but she would keep close tabs on me through her team members. For example, I bumped into my psychiatrist when I was volunteering at the hospital. She had already known from her team member (with whom I had met the previous day) that I had visited a family member in Toronto the previous week! Overall, my transition from hospital to the community went well. I knew that if at anytime I needed to see my psychiatrist, the team would be in touch with her right away and I could get an appointment to see her almost immediately.

Despite my overall positive transition experience, I found that the information from the staff at The Royal was not shared very well at first with the psychiatrist on the ACTT. Initially, the ACTT psychiatrist wanted to put me on a Community Treatment Order (CTO) so someone on the team could visit me every night to ensure that I was taking my medications. What was not communicated with the ACTT by the hospital staff was that I was very compliant with my medications in hospital and I agreed to take them voluntarily at home. Eventually, they decided against a CTO, but the stress that this situation caused me could have been avoided had there been better communication between the hospital and the community teams.

Apart from the care providers within the ACTT, my daughter played a big role in my transition from hospital. Although she was just a teenager at the time, she always managed to come visit and help out with anything I needed at home.

3. What could have been done differently to make the experience better for you?

Overall, my transition experience was quite positive. However, if the ACTT had anticipated some of my needs prior to discharge, perhaps I would have felt less overwhelmed and anxious.

For example, knowing that I had not managed a budget or grocery shopped in years, the ACTT staff could have worked with me on those skills after my hospitalization.
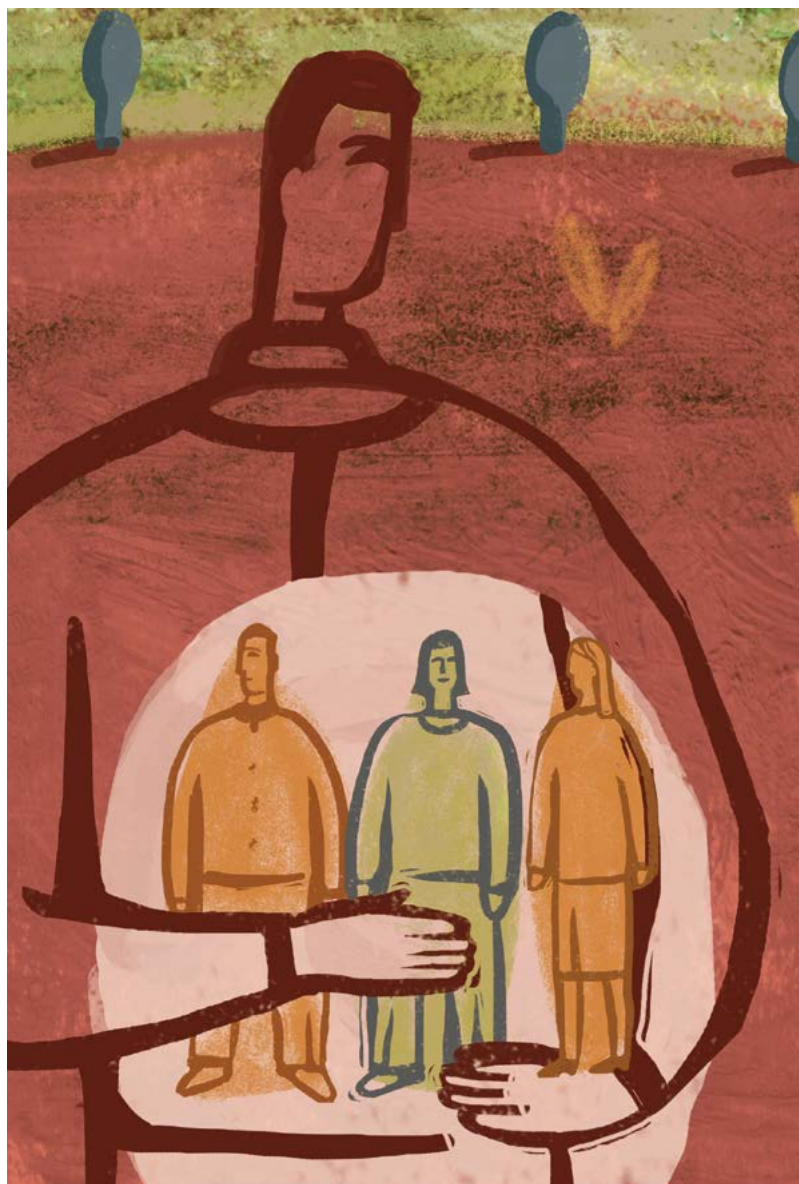
Early Results: Patient Experience Across Transitions in a Bundled Model of Care

By: Sydney Jopling, Kevin Walker and Walter P. Wodchis

Fragmented and poorly coordinated care throughout episodes of care involving multiple providers, and particularly at points of transition between levels of care, can put patients at risk for adverse health events and less than optimal quality of life outcomes. Research demonstrates that poorly managed care transitions also negatively affect patients' and caregivers' experience of and satisfaction with care. To address this issue, Ontario and many other jurisdictions have undertaken numerous initiatives to ensure a seamless care experience for patients and families. Care transitions have long been a focus of improvement efforts, largely because ineffectively managed transitions have been associated with increased hospital readmission rates and costs.

Care transitions have long been a focus of improvement efforts, largely because ineffectively managed transitions have been associated with increased hospital readmission rates and costs.
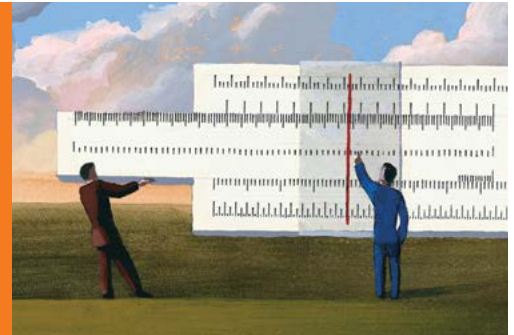
Bundled care is an intervention that evolved out of the effort to reduce hospital readmission rates and also targets many of the elements of care transitions, such as patient education, discharge planning, medication reconciliation, and timely follow-up (see Box 1).

The Ontario Ministry of Health and Long-Term Care (MOHLTC) introduced its own bundled care initiative in February 2015 with the Integrated Funding Models (IFM) pilot project. The objective of the pilot project was to test innovative approaches to integrated (i.e., bundled) funding for a specific episode of care and to coordinate resources across acute and post-acute care settings.

The MOHLTC put out a call for proposals, for which applicants were free to choose their episode of focus (e.g., congestive heart failure, stroke, cardiac surgery, urinary tract infection, etc.), design their care pathway, select the length of the bundle period, and decide which health care providers were included. Six programs across six Local Health Integration Networks (LHINs) were selected to take part in the pilot project.

The Health System Performance Research Network (HSPRN) was tasked by the MOHLTC to conduct a central evaluation of the IFM pilot program and to measure patient experience with each of the programs.

This article describes the patient experience with acute care, post-acute care, and across the transition from hospital to home and the community in an integrated model of care based on a survey of patients enrolled in the six selected programs.

Questions common to both the IFM Patient Experience Survey (PES) and the Canadian Patient Experience Survey – Inpatient Care (CPES-IC) were used to compare IFM patients' experience with hospital care and discharge with that of other medical and surgical patients discharged from Ontario hospitals (see Box 2). HSPRN received aggregate CPES-IC data from the Ontario Hospital Association.

There were seven questions related to patient experience common to both the IFM PES and CPES-IC. The proportions of top-box response, which refers to the most positive response option, were compared between samples.

Findings

Sample Size

Between April 1, 2016 and March 31, 2017, 3,034 patients were enrolled in the six IFM programs, 1,007 of whom provided permission to share contact information with HSPRN. A stratified random sample of up to 20 patients per program, per month were selected. Out of 770 patients who were contacted for consent to participate in the PES, 431 patients completed the survey and were included in the results (approximately 56.0 per cent response rate).

The CPES-IC was administered by NRC Health at more than 60 acute care hospitals across Ontario between April 1, 2016 and March 31, 2017, sampling a total of 99,892 patients. Of those sampled, 37,084 patients completed the survey (39.2 per cent response rate).

Unfortunately, it was not possible to compare the IFM PES and CPES-IC samples in terms of demographics; most of the questions differed between the two surveys, and for those questions that were relatively similar (e.g., age, race/ethnicity), the surveys provided different response options.

Box 1

Bundled Care Model: Quick Facts

Bundled care is a model of service delivery that packages services from multiple providers into a single care pathway (Jacobs et al. 2015), allowing for improved coordination and continuity of care across the continuum of care settings and providers (Ouwens, Wollersheim, Hermens, Hulscher & Grol, 2005; Goddard & Mason, 2017).

Bundled care models are patient-centred; they wrap care around the patient (National Collaboration for Integrated Care and Support, 2015) and have been shown to improve patient satisfaction with care (Mason et al., 2015). Many bundled care models also bundle funding by using a single, fixed payment to cover the entire package of services across multiple providers (Jacobs, Daniel, Baker, Brown & Wodchis, 2015).

Box 2

HSPRN Patient Experience Survey

The HSPRN developed a novel survey tool that measures patient experience across multiple care settings, combining items from a number of existing, validated surveys – including the CPES-IC. Data collected with the IFM PES is not evaluative; it was intended as a quality improvement tool for the IFM programs, who received monthly or bimonthly reports with aggregate results and anonymous patient comments.

Canadian Patient Experience Survey – Inpatient Care

The CPES-IC is a pan-Canadian survey that was developed in 2011 by the Canadian Institute for Health Information (CIHI) based largely on the U.S. HCAHPS survey. It measures patient experience with acute adult inpatient care (CIHI, 2015a).

Survey Results

Experience in Hospital
In hospital, IFM patients reported a similar experience to the general Ontario population. While results from the four common items (Table 1) did not differ significantly at p<0.05, IFM PES respondents answered slightly more positively regarding information given in hospital, reporting that they received the information they needed about their condition and treatment more often than CPES-IC respondents: 65.7 per cent of IFM patients sampled responded "Always" as compared to 61.6 per cent of patients completing the CPES-IC (P=0.093; Figure 1).

Experience with Discharge from Hospital
There were mixed results for questions regarding preparedness for discharge and discharge planning (Table 2). IFM patients reported a significantly better experience than CPES-IC respondents with respect to discussions with hospital staff about the support they were going to receive after discharge (IFM, 89.9 per cent "Yes" vs. CPES-IC, 76.9 per cent, P=0.000; Figure 1). These results are not surprising, as each of the IFM programs stipulated a structured care pathway in the community after leaving the hospital, with varying levels of care depending on patient need.

In contrast, the IFM programs did not have a strong performance in patients' understanding of their medication, an element of transitions where one would expect to see improvement in a bundled care model. Notably, approximately 30 per cent fewer IFM PES respondents strongly agreed that they clearly understood the purpose for taking their medications compared to CPES-IC respondents (IFM, 47.5 per cent "strongly agreed" vs. 76.5 per cent CPES-IC, P=0.000; Figure 1). These results may be associated with medication reconciliation in hospital, but may also be affected by characteristics of the target patient population of the IFM programs; many of the programs focused specifically on patient populations with a high degree of multi-morbidity, which may be associated with a high number of medications. The greater complexity of the IFM PES patient sample is reflected in the patient reported outcomes, where IFM PES respondents were more likely to rate their physical health as "Poor" or

Table 1: IFM PES and CPES-IC questions related to experience in hospital

IFM PES	CPES-IC	Question
Question 1	Question 30	Do you feel that there was good communication about your care between doctors, nurses and other hospital staff?
Question 2	Question 32	How often were tests and procedures done when you were told they would be done?
Question 3	Question 33	During this hospital stay, did you get all the information you needed about your condition and treatment?
Question 4	Question 34	Did you get the support you needed to help you with any anxieties, fears or worries you had during this hospital stay?

Table 2: IFM PES and CPES-IC questions related to experience with discharge from hospital

IFM PES	CPES-IC	Question
Question 7	Question 37	When you left the hospital, you clearly understood the purpose for taking each of your medications? CPES-IC version: Before you left the hospital, did you have a clear understanding about all of your prescribed medications, including those you were taking before your hospital stay?
Question 9	Question 38	Did you receive enough information from hospital staff about what to do if you were worried about your condition or treatment after you left the hospital?
Question 10	Question 19	During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?

"Fair" and less likely to rate it as "Very Good" or "Excellent" than the CPES-IC sample (see Figure 2). The IFM PES patient sample also reported less positive outcomes than the CPES-IC sample in terms of self-assessed mental health status (Figure 2).

There was no statistically significant difference in the percent of top-box responses between IFM PES and CPES-IC respondents when asked if they received enough information about what to do if they were anxious about their condition or treatment after leaving the hospital (IFM, 54.8 per cent vs. CPES-IC 58.2 per cent, P=0.174; Figure 1).

Experience in Community
Standardized questions about patient experience in the community after leaving hospital were not included in the CPES-IC. The authors, therefore, had limited published comparable results for Ontario, with the exception of The Commonwealth Fund 2014 survey.

Figure 1: IFM PES versus CPES-IC Top-Box Results
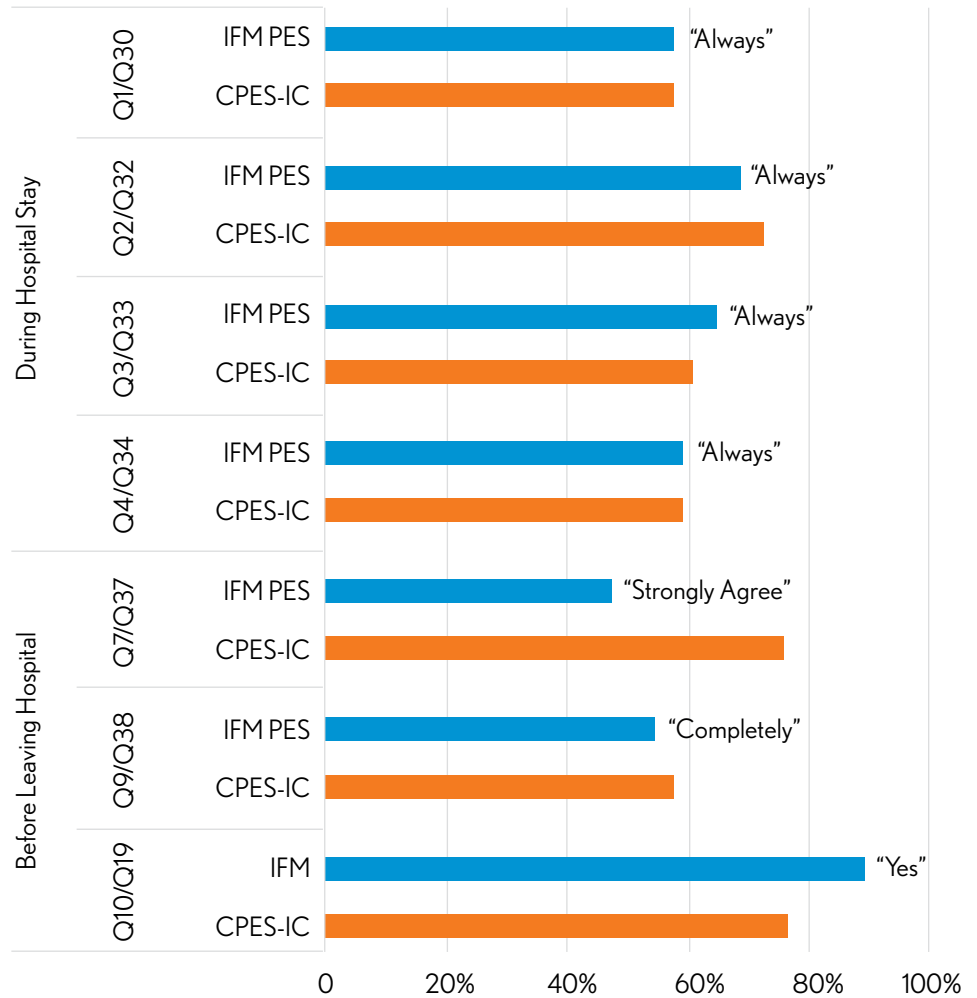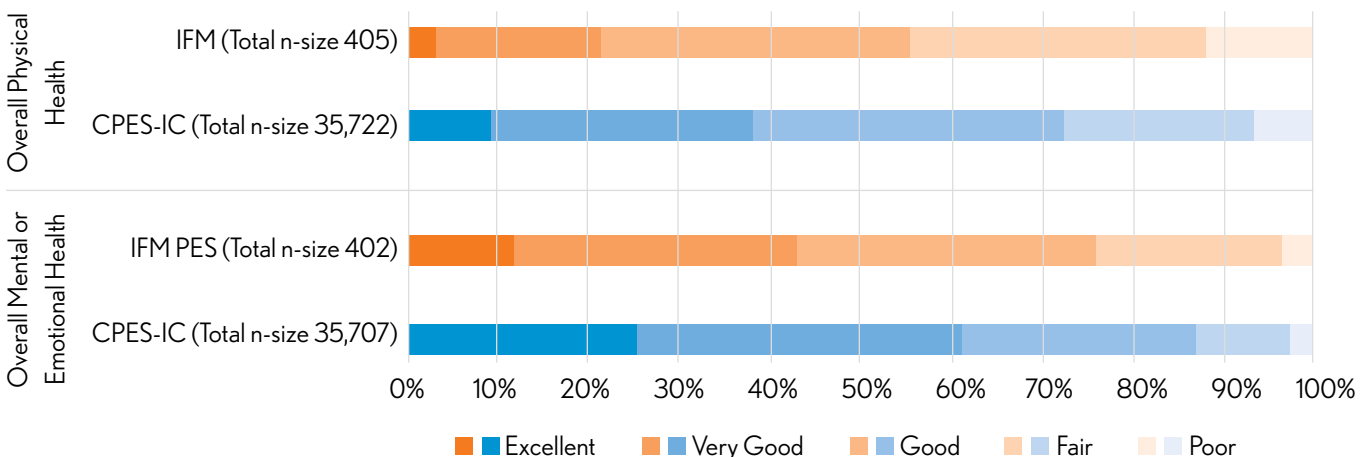(Please see Tables 1 and 2 for questions)

Figure 2: IFM PES versus CPES-IC Patient Reported Health Outcomes

The novel IFM PES survey tool provides an important contribution to the measurement of patient experience with bundled care, and allows researchers and stakeholders to measure patient experience both in the hospital and following their transition out into the community.

Information transfer from the hospital to community providers (including primary care) as perceived by IFM respondents was an area of excellent performance. 88.3 per cent of the IFM patient sample indicated that their primary care practice, or the location where they usually received care, seemed informed and up-to-date about the care they received in the hospital compared to 82 per cent of Ontarians who responded to the 2014 Commonwealth Fund Survey who indicated that their place of usual care was up-to-date about care they received from a specialist (CIHI, 2015b); and 90.8 per cent of IFM PES respondents answered "Yes" when asked the same question with regards to the health care team in the community (i.e., health care providers associated with the bundled care program). Despite very positive ratings of information transfer from the hospital to community providers, only two-thirds of IFM PES respondents answered that they never received information from providers in the community that conflicted with information given in the hospital. Similarly, only 67.0 per cent thought that there was never a time that changes to the treatment plan were

not communicated amongst providers. So, while information is transferred between settings, there is room for improvement in communication if this information is changed over the course of the episode.

When asked if there was one person that ensured the follow up of their care, 81.9 per cent of the IFM PES patient sample selected "Yes". These results reflect that five of the six IFM programs embedded a designated care coordinator into the care pathway.

Final Thoughts

As far as the authors are aware, the IFM PES represents the first survey tool that measures the patient experience from acute through post-acute care. Such a tool is invaluable to better understanding care across multiple settings throughout a care episode, an understanding that is vital to the patient experience, and more importantly, to health outcomes and quality of care.

This preliminary investigation showed that on most questions about their care experience, patients in the MOHLTC's IFM initiative reported similar ratings to other Ontario hospital patients. IFM programs

performed better than other hospitals in Ontario on some patient experience items related to care transitions, including information delivered to patients in hospital and communication with patients about post-discharge support. In addition, information transfer from hospital to the community and care coordination received excellent ratings from IFM patients. However, the results also indicated that patient understanding of medications prior to discharge from acute care (perhaps related to medication reconciliation) presents an area for improvement.

A limitation of this work is the lack of controlling for differences in the IFM PES and CPES-IC patient samples. Poorer self-reported health status, potentially indicative of higher levels of complexity in the IFM patient population, may have important implications for the results presented here and may limit comparability of the IFM PES and CPES-IC results. The IFM programs targeted patient populations where clinical outcomes and patient experience were thought to be sub-optimal. However, CPES-IC results currently cannot be limited to specific (comparable) clinical populations and a fully comparable sample could not be identified. Furthermore, while stratified random sampling was used, there was a large proportion of IFM patients who did not provide permission to be contacted by researchers, as well as some who once contacted did not wish to participate for various reasons (e.g., too ill, uncomfortable responding in English). As such, the authors cannot be certain that the results from the sample are representative of the entire IFM patient population.

Three additional insights stem from our experience with the IFM PES. First is the added value of being able to use patient experience surveys to assess the experience of specific clinical groups. Adding this capability to the general CPES-IC will greatly enhance our ability to identify subpopulations with high opportunities to improve patient experience. Second, the use of PES data to measure patient experience is central to the evaluation of health systems and even to include as part of joint accountability and remuneration in episode-based bundled care initiatives. Third is the importance of engaging patients directly in the selection of patient experience survey questions. The IFM PES and the CPES-IC were created by survey experts and stakeholders and may not fully represent outcomes of importance to specific populations, nor reflect all services received during the bundle period for all patients (e.g., there were no questions on the IFM PES specific to inpatient rehabilitation).

Despite these limitations, the novel IFM PES survey tool provides an important contribution to the measurement of patient experience with bundled care, and allows researchers and stakeholders to measure patient experience both in the hospital and following their transition out into the community. The IFM PES survey tool demonstrates the importance of continuing to develop and validate tools that allow researchers and stakeholders to better understand patients' experience of care as they move across sectors in the health care system.

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Enhancing Care Transitions and Discharge Planning

How the Markham Family Health Team integrated interdisciplinary health professionals to improve patient outcomes and experiences

By: Dr. Allan Grill

In 2015, the Markham Family Health Team (MFHT), which is affiliated with Markham Stouffville Hospital (MSH), launched the Transitions Program in response to feedback from our patients about their hospital discharge experiences. In particular, some patients (e.g., frail, older adults) had noted difficulties in arranging their own follow-up care.

While care transitions involve various settings including, but not limited to, emergency rooms, hospitals, rehabilitation facilities, nursing homes, and outpatient specialty clinics coupled with multiple clinical providers (e.g., physicians, physiotherapists, social workers, nurses, etc.), discharge from acute care to another care setting often puts patients at greater risk for sub-optimal care if not properly coordinated (HQO, 2013a; HQO, 2016).

Surprisingly, 20-30 per cent of emergency room patients presenting with exacerbations related to Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF), or diabetes do not arrange follow-up appointments within 30 days.

Moreover, patients often have multiple questions regarding medication changes and test results, and discovering their primary care provider (PCP) has not been fully informed adds to their list of worries.

The Markham Family Health Team incorporates the phrase 'Care for a Lifetime' in its mission statement. Established in 2007, the FHT consists of physicians and interdisciplinary health providers to manage the primary care of 27,000 patients.

PCPs, which include family physicians as well as nurse practitioners, play an especially important role in care transitions as the frontline coordinator of a patient's care. Keeping them informed can help patients understand their discharge plans, avoid getting lost to follow-up, and prevent any further decline in their health (HQO, 2016).

Prompted by the feedback provided by patients, Dr. Steve McLaren, a family physician at MFHT, decided to investigate whether the FHT could address the above-mentioned unmet care gaps identified by patients. In partnership with MFHT nurse Danielle Meads, he performed a needs assessment using outpatient electronic medical record (EMR) data. This led to the development of a draft list of goals that could be achieved if a nurse from the MFHT assisted with hospital discharge planning; these included:

- Sharing diagnostic information – patients could be better educated about their medical condition(s) and reason for hospital admission (HQO, 2013a; HQO, 2016). This could reduce patient anxiety and confusion given that only 59.6 per cent of inpatients can accurately describe their diagnoses (Kripalani, 2017).
- Continuity of care – patients can be reassured that their PCP is aware of their hospitalization. This improves overall communication (HQO, 2016).
- Discharge planning – patients can receive assistance with arranging follow-up services (e.g., removing

surgical staples, newborn weight checks, house calls, home care visits, etc.) promptly with the appropriate clinical provider (HQO, 2016). This would increase accountability as only 43.9 per cent of patients can accurately recall upcoming follow-up appointments (Kripalani, 2017).

- Arranging a post-discharge medication reconciliation with the MFHT pharmacist (HQO, 2016; Kripalani, 2017) .

Approximately one-third of patients have difficulty understanding their discharge medication regimen.

An important next step was to build stakeholder relationships by meeting with the MSH leadership. This helped staff better understand hospital workflow, identify which inpatients had the greatest needs, and address existing gaps in hospital discharge planning related to primary care. Working together with MSH enabled access and training on the hospital EMR system in order to track MFHT patient admissions in real time.

At present, the program is resourced with an administrative staff person who searches the MSH EMR system for MFHT admitted and discharged patients on a daily basis (Monday through Friday). A full-time registered nurse (RN) then receives this list and arranges visits to patients in hospital, or follow-up phone calls for those who have been discharged. Other discharge planning activities include:

- Newborn assessments in hospital along with the arrangement of a three-day follow-up home visit;
- Arrangement of follow-up home visits, in-office visits, and communication with home and community care organizations regarding service provision;
- Internal referral to other MFHT programs and services; and
- Documentation of notes within the MFHT EMR to update the patient's PCP.

Collecting data to determine whether the Transitions Program is having a positive impact on patient outcomes and experiences is also underway. An RN uses EMR tracking codes to help measure various services, such as total number of assessments, readmissions within 30 days, and average time before an office follow-up appointment takes place. Qualitative feedback from patients and caregivers is also being recorded.

Efforts to reduce hospital readmissions through improved care transitions are a health system priority in Ontario (MOHLTC, 2011; HQO, 2013a; HQO, 2013b; HQO, 2016). PCPs can play a crucial role in achieving this goal through improved stakeholder collaboration within a patient's circle of care.

The MFHT Transitions Program is an innovative model aimed at enhancing hospital discharge planning, continuity of care and patient and provider satisfaction. Ongoing quality improvement research and analysis using EMR data, as well as experience data from patients in this area, is required to determine measurable benefits.

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Improving the Hospital Discharge: Focus on Sustainability

By: Andrew Appleton MD, MHSc, CHE, FRCPC

Care transitions are critical stages in a person's health care journey. However, there is a body of evidence suggesting that patients are not receiving the communication or information they need at these critical transition points (Eassey, McLachlan, Brien, Krass & Smith, 2017; Rustad, Furness, Cronfalk & Dysvik, 2016). This leads to poor patient experiences and the risk of suffering adverse events, such as medication errors or disrupted continuity of care (Auerbach et al., 2016; Rustad et al., 2016). This phenomenon has more to do with sub-optimal discharge processes, than the well-intentioned providers who execute them.

Fortunately, improvement research has shown a better way, one that focuses on communication and places patients at the centre of their care (Jack et al., 2009; Sanchez, Douglass & Mancusso, 2015; Clancy, 2009). Research has also been shifting to an approach informed by patients' experiences with respect to continuity of care (Auerbach et al., 2016). However, sustainable implementation is a challenge in the real world.

This article examines why programs that have successfully addressed these gaps in care are challenging to replicate beyond the pilot phase, thereby making widespread improvement an elusive goal.

> By anticipating, evaluating and addressing sustainability challenges at all stages of planning, high-quality discharge process improvement can become a reality.

Ontario's Capacity Challenge

Further context for this article is the significant volume demand on the acute care system in Ontario. This will increase as the population ages (CIHI, 2011). Emergency department wait times, inpatient units operating above 100 per cent capacity, delayed hospital discharges, and high readmission rates are all symptoms of a strained system (CIHI, 2012). The act of discharging a patient from hospital is only one point along the journey through acute care. However, getting it right is crucial, helping to relieve pressure on the system, and most importantly, to support better patient experiences and outcomes. As such, the discharge planning process continues to be a focus of improvement efforts for health care providers.

The Difficulty in Replicating the Success of Project RED

The Project RED (Re-Engineered Discharge) study, which originated in the United States, proved that patient education and open lines of communication during and after hospitalization are beneficial (Jack

et al., 2009). The RED process included three strategies. First, the patient received education tailored to their reason for admission and comorbidities. Next, an after-hospital care plan was assembled. This document included the reason for hospitalization, a list of discharge medications and instructions, contact information, and a list of follow-up plans. The plan was discussed with the patient on the day of discharge and a copy was sent to the primary care provider. Finally, a pharmacist phoned the patient within four days of discharge to review medications and the overall plan.

The results of the study are compelling. Hospital utilization within 30 days of discharge was reduced by 30 per cent, patient satisfaction improved, and an estimated $412 USD per patient was saved (Jack et al., 2009). It is important to highlight that this was a general medicine population with a large proportion of lower socioeconomic status participants in inner-city Boston – a challenging population in which to elicit positive health outcomes. Following the publication of Project RED, national quality standards in both the United States and Canada have emphasized the discharge process as an opportunity to improve quality of care (AHRQ, 2013; HQO, 2013). Despite this policy direction, implementation of RED-like processes have been limited and disappointing.

A follow-up study to Project RED provides insight into the lack of uptake (Mitchell et al., 2016). Ten hospitals were observed for one year while they sought to implement

Following the publication of Project RED, national quality standards in both the United States and Canada have emphasized the discharge process as an opportunity to improve quality of care.

Project RED. Several themes became clear. First, organizations adapted the original protocol to better align with their current processes in 9 out of 10 cases. This diluted fidelity may have hampered the potential to realize the intended outcomes. Next, successful implementation was associated with strong leadership and teamwork. This is not surprising, but also cannot be taken for granted. Finally, there were common challenges across organizations which included acquiring additional resources, inflexible technology solutions, the need for clinical champions, the perception of duplication of work, and adapting to a new culture. At the end of the observation year, 7 out of 10 hospitals had implemented a version of RED. However, the outcomes were modest compared to the original study (Jack et al., 2009).

Clinical trials are strictly controlled environments. Recreating their results in the real world is nearly impossible. This is especially so when extrapolating the possible impact of study protocol to a population or environment that is different from the original. This is illustrated by the difficulties described in the Project RED follow-up study on implementation. Compounding this phenomenon is

that care delivery processes rely on people in organizations to perform them. Hence, most of the barriers to successful implementation are rooted in organizational priorities and culture. These barriers are not novel. They can be anticipated and addressed proactively to foster the best chance for success. The National Health Service (NHS) Sustainability Model, developed in the U.K., is a viable tool that can address this challenge.

Using a Model of Sustainability to Support Uptake

The NHS Sustainability Model can be used during improvement efforts to assess and address implementation challenges in the short and long term (NHS, 2006; Doyle et al., 2013). The NHS model is a survey tool completed by the project team at multiple stages of their work. For example, team members would individually complete the survey at planning, piloting and implementation checkpoints. The aggregate results would be discussed by the team, with relevant course corrections made thereafter.

The model assesses process, staff and organizational factors. Process factors address the real added value of an intervention. These include

Most of the barriers to successful implementation are rooted in organizational priorities and culture.

benefits beyond helping patients, credibility of the evidence-base, and effectiveness of the system to monitor progress. Attitudes toward change, training needs, and the level of engagement from administrative and clinical leaders make up the staff factors. Finally, organizational factors include strategic fit and whether existing infrastructure is suitable to support a new process. Together,

these aspects of an implementation effort support and enable the sustainability of a given intervention such as Project RED. Unaddressed weaknesses in any of the factors increase the likelihood of wasted effort. Failed implementation, in turn, bolsters people's unwillingness to change, opting instead for the comfort of the status quo.

Conclusion

Beyond Project RED, there are other helpful resources, tailored to Ontario's environment, to guide organizations on implementing better discharge practices. For example, the Patient-Oriented Discharge Summary (PODS) from University Health Network's OpenLab is a streamlined, patient-centred document that frames communication between hospital providers and patients (Hahn-Goldberg, Okrainec, Damba & Huynh, 2016). However, implementing a simple solution like PODS requires concerted team effort, for the reasons outlined above. Assembling the right

The NHS Sustainability Model (2006)

interdisciplinary team, including patient representation, and applying a framework for sustainability such as the NHS Sustainability Model throughout the improvement process, will create the best possible chance for success.

Patients deserve the best care that can be offered, especially during times of transition. Realizing this demands an imperative to continuously re-examine and improve processes. Each examination of the hospital discharge process provides an opportunity to firmly place the patient back at the centre of their own care. To do so, discharges must involve the patient, allow open dialogue, and focus on the information that matters to them. This not only improves the patient experience, but also bolsters efficiency and quality of care, while reducing cost (Jack et al., 2009; AHRQ, 2013; HQO, 2013).

Now is not the time for more pilot projects, now is the time for implementing sustainable, patient-centred discharge practices to improve patients' experience across care transitions.

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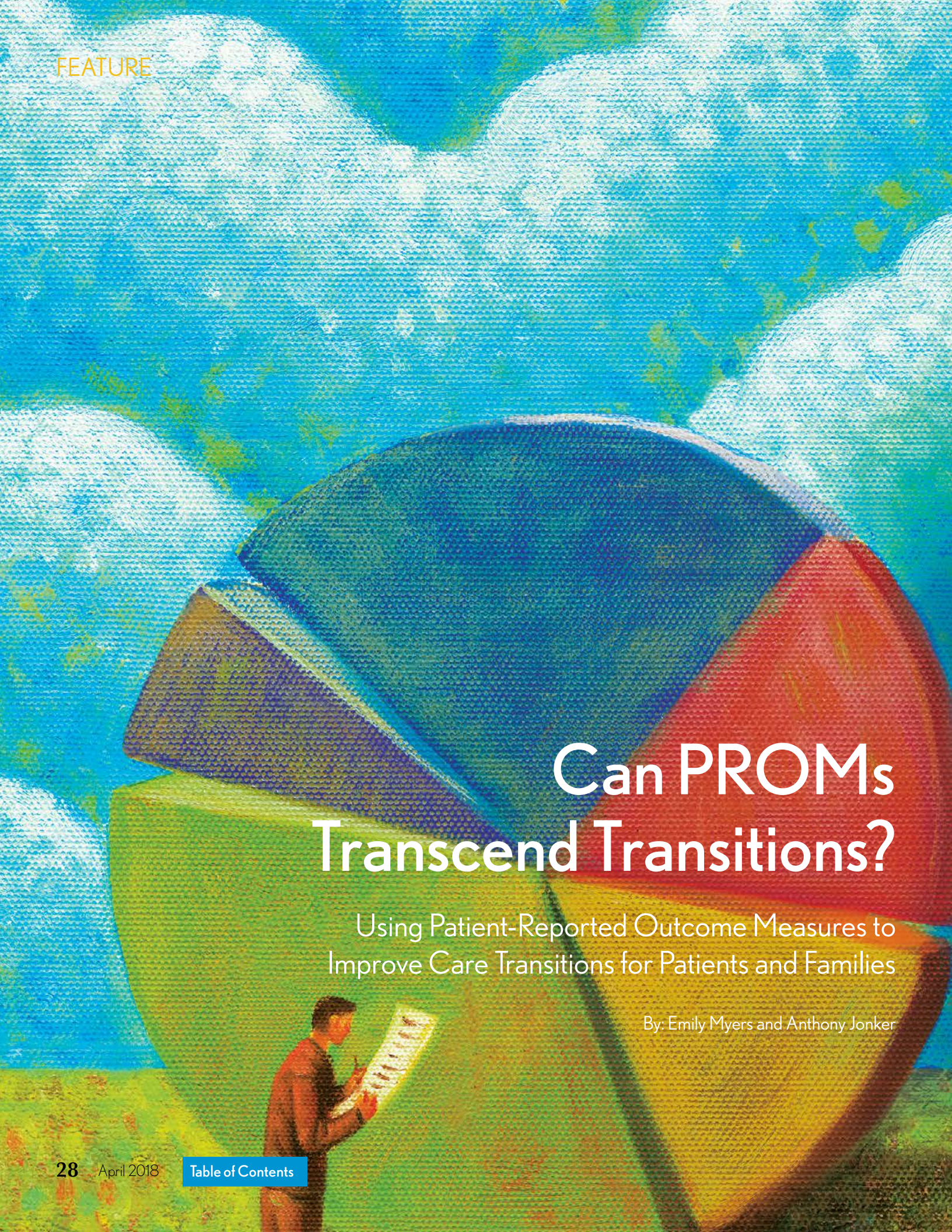
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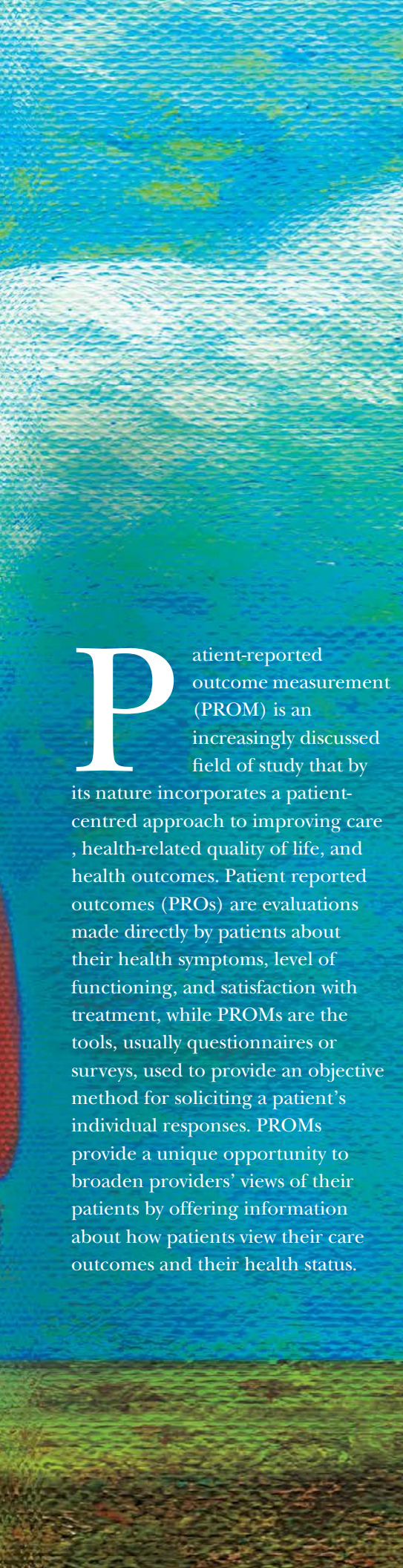
Can PROMs Transcend Transitions?

Using Patient-Reported Outcome Measures to Improve Care Transitions for Patients and Families

By: Emily Myers and Anthony Jonker

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Although standardized use of PROMs across many conditions and treatments is not yet part of current practice in Ontario, the swell of international interest is moving the discussion to expand systematic use of PROMs to new clinical areas.

Patient-reported outcome measurement (PROM) is an increasingly discussed field of study that by its nature incorporates a patient-centred approach to improving care, health-related quality of life, and health outcomes. Patient reported outcomes (PROs) are evaluations made directly by patients about their health symptoms, level of functioning, and satisfaction with treatment, while PROMs are the tools, usually questionnaires or surveys, used to provide an objective method for soliciting a patient's individual responses. PROMs provide a unique opportunity to broaden providers' views of their patients by offering information about how patients view their care outcomes and their health status.

Although valuable in promoting a patient-centred view, PROMs have not typically been implemented to communicate outcomes across transitions in care. There may be benefits if future PROMs could be adopted to equip a wider set of health care providers with each patient's perspective about their health status at various points in time as they transition across the continuum of care. Providers and care teams could use this information to create holistic care plans that reflect health status and quality of life from the patient's perspective.

What are PROMs and why are they important?

PROMs assess aspects of a patient's health status related to their quality of life, including symptoms, functionality and physical, mental and social health (CIHI, 2015). PROMs aim to capture the patient's perspective of their individual response to health interventions and treatments. Relying on clinical outcome data only, may miss the patient perspective completely. The PROs derived from PROMs tools have the potential to be an important measure of success for clinical providers and hospitals and provide an additional, highly patient-oriented measure against which to improve care.

Generic PROMs are utilized at an aggregate level in several Canadian provinces. PROMs for specific conditions, such as hip and knee replacements, are also administered in Ontario by some providers, as well as some other Canadian provinces, including Manitoba, British Columbia, Alberta, Saskatchewan and Quebec. PROMs are administered in Ontario at a standardized, system level for cancer care. Cancer Care Ontario (CCO) has been collecting data from PROMs since 2007 and holds one of the largest symptom databases in the world, with 30,000 new PROs collected every month. Access to this cancer PROMs data has enabled clinicians to look beyond disease or treatment outcomes to a more holistic approach, enabling clinicians

PROs vs. PROMs vs. PREMs

Patient Reported Outcomes (PROs) provide reports from patients about their own health, quality of life, or functional status associated with the health care or treatment they have received.

Patient Reported Outcome Measures (PROMs) are tools and/or instruments used to report PROs.

Patient Reported Experience Measures (PREMs) are tools used to measure and report patients' experiences during the care process.

Source: (Weldring & Smith, 2013)

to improve quality of clinical care as well as address quality of life from the patient's perspective (CCO, 2016).

Although standardized use of PROMs across many conditions and treatments is not yet part of current practice in Ontario, the swell of international interest is moving the discussion to expand systematic use of PROMs to new clinical areas. Health care leaders across the world are recognizing the value of PROMs. In the United Kingdom (U.K.), the collection of PROs is mandatory for some groups of surgical patients (Weldring & Smith, 2013). Another example is in the United States (U.S.), where PROs have been collected for orthopedics for a number of years. In 2007, the UMass Memorial Arthritis and Joint Replacement Center implemented a system designed to combine PROs data and clinical data within the patient health record, informing

discussions with patients about their care and care decisions (Ayers, Zheng, & Franklin, 2013).

How can PROMs drive patient-centred care across transitions?

Designing PROMs for implementation across transitions at the outset, unlike the traditionally siloed approach that was developed with PREMs (see Box 1 for the definition), enables them to be a useful tool not just for local, site-specific quality improvement initiatives, but for augmenting clinical conversations and quality of care across the full patient journey.

One of the key challenges for patients in transition, particularly those with complex conditions, is that each new provider can too often see the patient as a point in time (the patient as I am seeing them today) or

through a particular clinical specialty lens (the patient's wound or failing joint, etc.), rather than holistically. PROMs tools present an opportunity to widen the lens with which providers see their patients by encouraging awareness of how the individual sees their core outcomes or functional health status. If PROMs are adopted in a way that bridges transitions, each provider would have a perspective of the patient's outcome across other providers and over time, enabling clinical conversations that reflect the whole patient.

There are a number of considerations with respect to implementing PROMs in this way:

1. **Standardize PROMs tools**
   The first requirement is a standardized set of questions to ask patients (a PROMs tool). This is important for a number of reasons. First, it creates a common language of PROs across providers, supplying informational continuity and thereby encouraging consistent conversations with patients across care setting.

   Second, it enables intra and inter-organizational benchmarking, which, in turn, can help identify where to look for organizational or systemic quality improvement opportunities. Furthermore, use of a standardized tool enables trending about how a patient fares over time. Additionally, and of significant relevance to a patient-centred approach, is that a standardized set of

questions across care settings reduces the burden on patients responding to a PROM tool on multiple occasions by creating a predictable, consistent (and preferably simple) process of participation.

The good news is that a variety of well-designed, generic PROMs surveys currently exist. Examples include the *Veterans RAND 12-item Health Survey* (VR-12), the *PROMIS Global 10* and the *EuroQol 5-dimension questionnaire* (ED-5D). It should be noted that the benefits of customizing PROMs for condition-specific

patient populations will sometimes be in tension with the ability to widely compare and benchmark. In some instances, PROMs have been developed for very specific patient populations, asking questions that are highly relevant to outcome and quality of life indicators typically associated with that condition. Some leaders in PROMs have attempted to work around this challenge by implementing generic PROMS, supplemented with condition-specific questions. This hybrid approach provides some confidence that, notwithstanding

these differing purposes, we can find a PROMs strategy that leverages a ubiquitous, generic PROMs tool that would function well across care settings.

The International Consortium for Health Outcomes Measurement (ICHOM) brings together international patient representatives, clinician leaders, and registry leaders to develop standard sets of clinical, administrative, and PROs they recommend all providers track where applicable. Through that work, ICHOM has developed recommended standard sets

of condition specific measures (e.g., dementia, pregnancy and childbirth, hip and knee osteoarthritis, etc.) that also leverage generic/global tools (ICHOM, 2017). Nevertheless, there is a lack of consensus around one generic tool and even ICHOM leverages a few different generic tools, depending on the condition. Within Ontario (if not beyond), it would be beneficial to utilize a common generic tool where possible, supplemented with condition-specific PROMs as needed, thereby increasing the amount of standardized PROs being incorporated into the patient record.

2. **Enable use across the patient journey**
Ultimately, adopting a standardized PROM is a precursor to its consistent implementation

in clinical settings across various points along the patient journey. Implementation includes both the administration of the PROM (obtaining the patient's response), but also the availability of the results for discussion between provider and patient during visits. Ideally, presentation of results would include those from previous responses, allowing for a longitudinal view.

Such implementation of PROMs to measure the full "cycle of care" for a particular condition is by no means a new idea and has been shown to be successful (Porter, 2014). The nuance in what we are proposing is the application of PROMs across transitions and the inclusion of results connected to providers and events across other care settings and over time. We believe that making the results of generic

and condition-specific PROMs available in this way could help equip clinicians with a more holistic view of patients and, perhaps, the creation of even more patient-sensitive care plans.

3. **Designate administrative accountability**
While it would be ideal to collect and report results of a standardized PROM across care settings, achieving this comes with significant challenges. One of these challenges is designating administrative responsibility and accountability for its implementation. Sustained practice may be easier to achieve if a lead organization could be identified (perhaps for each clinical condition) to have responsibility for the collection and sharing of PROs throughout the entire patient journey, as CCO is doing for cancer care. This single organization would oversee the accountability structures and organizational cultures that promote participation and sustainability. Ideally, it would also manage the value proposition for collecting PROs, considering benefits in light of effort and administrative costs.

Our system in Ontario is not currently organized in such a way as to support this approach widely. Due to the administrative accountability challenges, the best available opportunities to apply PROMs across transitions may be through an integrated, bundled care model such as those being piloted in Ontario.

> Similar to other system challenges faced in health care, having a shared electronic health record in place would be a significant enabler for solutions and its ongoing development is an inherent challenge of this approach.

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Such single organization-led, continuity of care initiatives may be what is required to ensure consistent and objective survey practices through the ongoing collection of PROs (pre-, post- and in-between clinical encounters) and display results within the shared record of the clinical care team. For example, surgical patients within an integrated care model where PROM results are available, tracked and measured not just at the surgeon's office but also with the primary care and rehabilitation teams.

4. **Disseminating the patient's voice**
Finally, success will require reporting PROs so they can be available for discussion across care settings. Similar to other system challenges faced in health care, having a shared electronic health record in place would be a significant enabler for solutions and its ongoing development is an inherent challenge of this approach. Again, piloting such a strategy as part of an integrated bundled care program, within which a shared record exists, may be a good place to start.

CCO's Interactive Symptom Assessment and Collection (ISAAC) system, which lets patients and their caregivers assess and track their symptoms online, is a provincial leader when it comes to including PROs within the patient's health record. CCO enables PROMs collection for cancer patients at kiosks in 14 regional cancer centres and 78 partner hospitals throughout the province. Approximately 30,000 patients are screened every month through ISAAC in Ontario (CCO, 2016) and these results form a regular part of discussions between clinicians and patients in Ontario's cancer centers. Finding a way to learn from this approach may help to bring the value of PROMs into more clinical conversations.

Conclusion

Piloting provincial, standardized PROMs tools through an integrated care model may provide an opportunity to introduce and test the use of PROs specifically designed to follow patients across transitions. Regardless of the method chosen, as interest in PROMs grows, it will be useful to think about how to design their adoption to ensure maximum benefit to patients and how they can reinforce consideration of the patient perspective not only at each visit, but also across transitions and care settings.

We have imagined what these next steps would be, including selecting a standardized PROMs tool(s), enabling PROMs use across the patient journey, designating administrative accountability and disseminating the patient voice. Though a challenging proposition, it begins with an agreement that listening to patient perceptions of their own outcomes and sharing those results across transitions should have a positive impact on care.

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Through the Eyes of Patients and Caregivers: Julie Drury

Redefining Health Care spoke to a number of former patients and caregivers to ask for their view about care transitions.

Julie is the inaugural Chair of the Minister of Health and Long-Term Care's Patient and Family Advisory Council (PFAC). Based on her personal and professional experience, she was appointed to help advise government on key health care priorities that impact patient care and patient experiences in Ontario. While managing her daughter's complex medical needs, Julie has mentored other families facing similar challenges, and helped them navigate the health care system. She has worked as a senior policy advisor and director with Health Canada, is a board director of MitoCanada Foundation, and has also been a family advisor with a number of organizations.

1. Can you describe an experience when you transitioned from one health care setting to another?

Over the course of my daughter's life, we experienced many care transitions: ICU to inpatient, hospital to home, hospital to home care, and hospital to hospital. In some instances, these transitions went well, while in others, they did not. Where transitions did not go well, the main issue was lack of communication between the health care providers, health care teams, and health care facilities.

Our family found that there was significant communication before and during admission (for the most part), particularly if the admission was planned (e.g., a surgery or procedure). However, there appeared to be a lack of communication and policy/mechanisms to ensure appropriate communication after a procedure, particularly if complications occurred.

Reflecting on one particular experience, we had a scheduled procedure for a surgery at one hospital that had been carefully planned with our primary care team at our 'home' hospital because of our daughter's complexity. Following discharge, we learned that our child's primary care team was not even made aware she'd been discharged home. Though our child appeared stable enough for discharge, she had a medical event on the drive home. We immediately took her to our 'home' hospital's primary care team, who had no information about her procedure, her recovery, or her discharge. In retrospect, had our child's primary team been involved in discharge planning (as they had been in planning the procedure), she would likely not have been discharged from hospital that soon, and the team would have been better prepared to support her during a medical event.

2. Can you reflect on how your transition impacted you and/or your caregiver?

Unfortunately in many of our experiences, information sharing was extremely poor and often left to the parents to coordinate and facilitate.

Over 90 per cent of the time, information sharing between different settings occurred because we facilitated it as parents. This was extremely stressful and put an incredible and unfair burden on myself as the primary caregiver for our daughter.

Care between settings was not linked and not holistic. Information sharing was very difficult and occurred either late or on an ad hoc basis. Discharge notes would arrive late (e.g., two to three days post discharge) and provide little useful information. There were no emails, phone calls, or discussions where questions could be asked or answered. This only occurred in 'crisis' situations and not proactively as part of good practice.

We were often told one thing, while another actually occurred. There was an appearance of engagement, but often, health care providers were absent from care transition conversations, there were constraints around Monday–Friday/9 a.m. – 5 p.m. ability to support transitions, and health care providers did not follow up on commitments made about care needs or preferences in transition planning (e.g., directly relaying information to our primary care team).

Because we are a highly engaged family who advocated strongly for our child, we made a significant effort to be involved in planning transitions. We also learned over the years what this should look like and what needed to happen to ensure proper care transitions.

The entire journey was a significant learning curve for us, and we feel this should not be the case for patients and their families.

3. What could have been done differently to make the experience better for you?

Every child/patient, particularly those who are known to be more medically complex, should have a well-organized discharge plan that includes input from the parents/family before discharge or a transition in care is made.

In my opinion, this would include the following:

- A discharge planning meeting that includes the key health care providers and patient and family involved in the case, held one to two days before discharge. This meeting would review both the plan and patient/family needs/preferences and address any questions or concerns.
- A discharge note that is reviewed with the patient and family first and sent to the health care team on the day of discharge (with a copy given to the patient and family). This should include important and relevant details determined in consultation with the patient/family (e.g., changes in medication, medication plan, wound care/management, emergency/crisis plan and contact etc.).
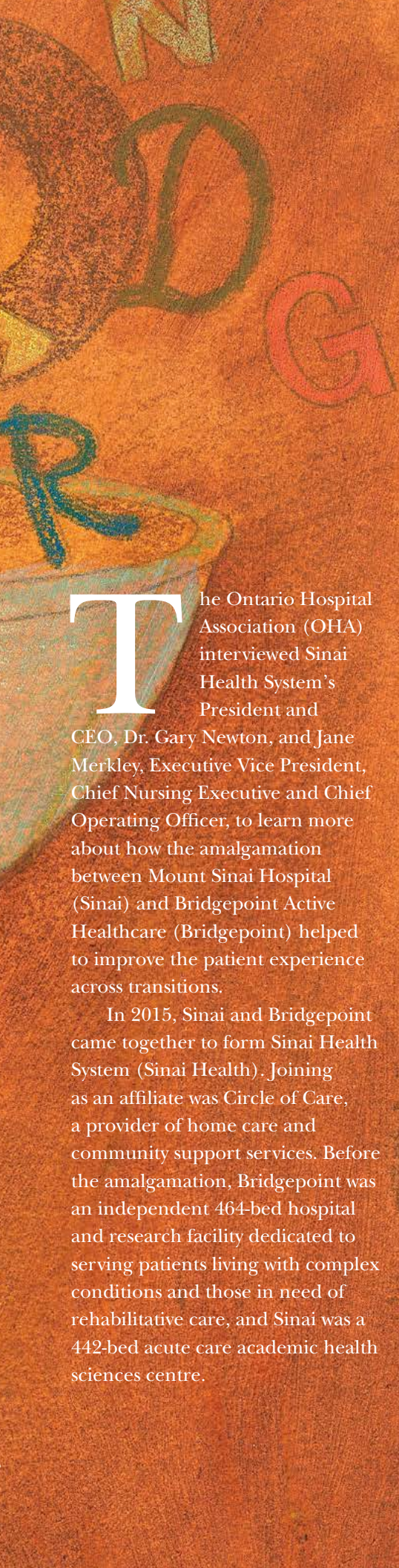
Merging Organizations

To Improve Continuity of Care for Complex Populations

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> **"For Sinai Health, the journey has been one that is deliberate and carefully planned. I view the date of the amalgamation [January 2015] as day one of the transformation that is still ongoing."**
>
> – Dr. Gary Newton, President & CEO, Sinai Health System

The Ontario Hospital Association (OHA) interviewed Sinai Health System's President and CEO, Dr. Gary Newton, and Jane Merkley, Executive Vice President, Chief Nursing Executive and Chief Operating Officer, to learn more about how the amalgamation between Mount Sinai Hospital (Sinai) and Bridgepoint Active Healthcare (Bridgepoint) helped to improve the patient experience across transitions.

In 2015, Sinai and Bridgepoint came together to form Sinai Health System (Sinai Health). Joining as an affiliate was Circle of Care, a provider of home care and community support services. Before the amalgamation, Bridgepoint was an independent 464-bed hospital and research facility dedicated to serving patients living with complex conditions and those in need of rehabilitative care, and Sinai was a 442-bed acute care academic health sciences centre.

According to Jane Merkley, both Bridgepoint and Sinai had already served among the most complex patients in the province pre-merger, and had a history of working together to improve care for their patients.

"We recognized early on that we both excelled in our respective areas of care, but together, we could do so much more for our patients," said Merkley. "The data shows that the vulnerability for complex patients is often in the transition periods between care settings, and we needed to get better at addressing the entire continuum of care for patients." If they could improve continuity of care, they could improve patient outcomes and patient and caregiver experiences. It soon became clear that Sinai, Bridgepoint and Circle of Care shared a unique opportunity to work under a single, compelling vision: "…creating a leading integrated health system for people with complex health needs".

Having a research mandate through the Lunenfeld-Tanenbaum Research Institute was also integral to exploring new, innovative models of care and reinforcing Sinai Health's commitment to innovation.

Implementing the Change

Dr. Newton, who became President and CEO in 2016 after serving as Chief Medical Strategy Officer and Physician-in-Chief when Sinai Health System was first formed, considers the day the merger was announced as the first day on Sinai Health's transformational journey: "Transformation is not organic or immediate; it's a deliberate, meticulously planned and well-managed process."

According to Merkley, a key ingredient that supported this transformation was the establishment of an Office of Transformation and Integration and the appointment of a Chief Transformation Officer, which helped to ensure purposeful change.

To date, this multi-year process is supported by research to ensure that evidence is guiding decision-making; by updating existing structures to emphasize system-wide leadership and establish organization-wide committees; and change management, through

extensive, ongoing communications with staff, physicians, patients and the community and a re-branding strategy.

"When you think that you've communicated the idea enough, communicate it more. You can't over-communicate a transformational agenda. We had the advantage of having a very appealing agenda, and the positive feedback and genuine excitement that we received when we talk about our vision to the staff is incredible," said Dr. Newton. "Our town halls, for example, are standing room only."

Quality Aims were also established to drive leading practices. Targets set for patient- and family-centred care included: to be a top 10 per cent performer in patient experience for continuity of care and transitions, and for informed care; to be a top 10 per cent performer in overall patient experience; and to ensure that 80 per cent of all corporate quality initiatives engage patients and families.

Developing New Models of Care

Patients were the core focus of this transformation, more specifically, improving continuity of care under the new vision. Merkley explained that the approach taken by Sinai Health was to initially zero-in on key populations, and they identified orthopaedics as an area where immediate gains could be made. The main question guiding the project in orthopaedics was: *"How can we create an integrated system for patients with complex orthopaedic conditions – such as those with hip fractures and joint revisions?"*

Experience-based co-design (EBCD) was regarded as the best strategy for answering this question, as it enables input from staff, patients and their families.

Input from patients and families proved to be invaluable; for example, they shared that they felt anxious about moving to Bridgepoint – they wanted to know about the environment and what to expect – and also expressed difficulties with pain management during transitions. In response, Sinai Health developed videos and brochures to orient patients and families to the new environment, and implemented pain management interventions that would ease the care transition from one care setting to the next. As well, to address transportation challenges raised by patients, two vans were made available through Circle of Care to transport patients between sites for the required six-week specialist follow-up appointments.

What is EBCD?

Experience-based co-design (EBCD) is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership. The approach is different to other service improvement techniques. EBCD involves gathering experiences from patients and staff through in-depth interviewing, observations and group discussions, identifying key 'touch points' (emotionally significant points) and assigning positive or negative feelings.

A good resource on the approach is The Point of Care Foundation based in the U.K.

Merkley was pleased to share that the efforts paid off:

- Patients' pain scores at the time of transition and in rehabilitation decreased.

- Patient experience scores improved, especially in the "continuity of care" domain as measured by the Canadian Patient Experience Survey-Inpatient Care.

- Members of the health care team communicated more effectively with one another.

- Patients no longer had to wait for access to specialists and early diagnostics. They could now get the care they needed in a timely manner, and avoid being transferred from one organization to another unnecessarily.

- Quality-Based Procedure (QBP) standards and targeted

"Transformation is not organic or immediate; it's a deliberate, meticulously planned and well-managed process."

performance goals were met, and in some cases, surpassed, such as time to surgery and expected length of stay in hospital. For example, the new orthopaedic care pathway was able to:

– reduce length of stay by 6.3 days,

– decrease time to surgery by 16 hours,

– increase the time of initiation of appropriate osteoporosis treatment by 40 per cent, and

– decrease cost per case by almost $5,000.

Merkley also noted that the success of the new orthopaedic integrated care pathway can be attributed to the close collaboration with patients, families and staff during the design. She added that staff continue to receive training on EBCD as a way to foster patient- and family-centred care when developing new, integrated care models.

Sinai Health has also begun working on two other care pathways, palliative care and medically complex patients/complex medicine.

According to Dr. Newton, high-quality end-of-life care had already been offered in Bridgepoint's 32-bed Albert & Tammy Latner Family Palliative Care Unit, Sinai's inpatient units, patients' homes through the Tammy Latner Centre for Palliative Care, and through Circle of Care's large ambulatory and community/home-based program. Sinai Health recognized the need to harness these extraordinary individual programs to establish an integrated, comprehensive clinical and academic program that focuses on innovative models of care.

Dr. Russell Goldman, Director of Sinai Health's Inter-Departmental Division of Palliative Care, is developing a system-wide approach to transforming the palliative care model, from primary care to hospital care, to home care. Now, palliative care physicians at Sinai can admit patients directly from home to inpatient palliative care in cases where patients who were being cared for at home had a sudden change in their condition. Patients no longer have to go through the emergency department to access inpatient palliative care. They can be transferred directly from home to a palliative care team who can provide them with the most appropriate and compassionate care.

The patient- and family-centred care approach has also cascaded to other valuable initiatives that can support these critical transitions for patients. According to Merkley, Sinai Health, Woodgreen and The Change Foundation are currently collaborating to look at strategies for supporting family caregivers so that they can help facilitate transitions for complex patients and enhance continuity of care. As part of these efforts, a new centre for family caregivers is being planned to provide a forum for caregivers to connect with one another and health care providers in order to obtain the supports they need.

With continuity of care top-of-mind, Sinai Health is broadening its partnerships with long-term care homes and retirement facilities. They are also exploring opportunities to work with other health care providers to build capacity in primary care.

Parting Thoughts

When reflecting on the 2015 merger, Dr. Newton recognizes that while the new organization presents an exceptional opportunity to provide more integrated care for patients, it still only captures a portion of an individual's entire care journey, which begins far before admission and encompasses more than just the hospitalization of a patient.

"We are only a part of the solution in achieving more seamless care across our health care system. There is a lot of impressive work being done in the province, and I believe we are an important partner in encouraging health care providers to work together to create a new system, one comprised of connections that make healing a continuous journey," Newton said.

Merkley believes that while structural change can help to spur better integration across traditional health care silos, the real work is in harnessing the desire for health care providers to lead and institute change, by inspiring them with a moving vision, giving them the right tools, and ensuring that patients and families are engaged in the process of transformation. "We've learned so much since we amalgamated, including that patient and family engagement is not just a nice to have, but that it's essential. And we are really seeing results in patient care, which is really what it's all about."

The inter-professional approach for hip fracture patients developed at Mount Sinai was featured in a study published in the *Journal of Orthopedic Trauma*. Dr. Christine Soong, Hospitalist, led the quality improvement initiative and study.

Through the Eyes of Patients and Caregivers: Crystal Chin

Redefining Health Care spoke to a number of former patients and caregivers to ask for their view about care transitions.

Crystal was diagnosed with a neuromotor condition at eight months. She moved to Canada from Taiwan in her late childhood and received care in paediatric hospitals until she transitioned to adult care. Crystal has made significant contributions to improving health care delivery by ensuring that the patient voice is heard. She has worked with organizations, such as Holland Bloorview Kids Rehabilitation Hospital, Health Quality Ontario, The Change Foundation and Patients Canada.

1. **Can you describe an experience when you transitioned from one health care setting to another?**

Transitions occur on a daily basis in all areas of life, and not just in health care. This process can frequently pose as a time of uncertainty. Our advancements in medicine and technology have allowed all of us to live longer, including individuals with congenital conditions and medical complexities, as well as individuals with chronic conditions who acquire other illnesses through the aging process. It is not enough to prepare youth and their families for these transitions along with a scattered number of sub-specialists and a few clinics throughout the country. It is essential to incorporate fundamental knowledge of childhood-onset conditions to equip current and future adult care providers throughout the health care system in understanding the needs of this population in order to plan and best assist the families and young adults who will inevitably graduate and transition into their professional practice. Yet, from my experience, there seems to be a lack of holistic integration in the adult system, which saddles the patient with all the responsibilities of sorting out logistics and coordinating and communicating between specialists, to ensure that things occur in a logical manner.

When I transitioned from paediatric to adult care, the number of providers tripled even though my health had not changed. At the same time, there was a decrease in home care support due to the assumption that I was now an adult, and that I would be more independent with my physical needs. However, the management of my care alone can sometimes feel like the equivalent of a full-time job.

Finally, transitioning with a congenital condition that can have multiple comorbidities, requiring numerous specialists, can be stressful. This is especially the case when coming from a wide-ranging, better integrated system of care which the person has likely known since childhood, to a compartmentalized and more fragmented one. Such an important transition can affect an individual's mental health

and overall wellness. I found that the adult system is quite limited in addressing this aspect of care for young adults.

Good continuity of care is a crucial way to ensure that individuals can maintain their participation in their community and remain active citizens in society. One way to support this is by having and implementing well-rounded policies developed using qualitative and quantitative research that explore different stages throughout life. This data would inform and enrich our understanding, and hopefully result in a more inclusive infrastructure. Respecting the capacity and autonomy of the person and/or their system of support, engaging in dialogue regarding the goals of the individual, developing a basic appreciation that what may have worked well in the past may no longer be feasible, and being cognizant of social determinants of health, may all be factors in care planning. We must be transparent in regards to our resources and limitations as a health care system, and align these elements with the preferences and priorities of the patient and their support system through honest discussion and negotiation.

2. Can you reflect on how your transition impacted you and/or your caregiver?

It is second nature for people to judge a book by its cover. It is critical to remember that physicians and other health care providers are also human, who, when faced with time and resource pressures, may end up leaning on stereotypes and biases when dealing with patients, rather than what they know or by getting acquainted with their patients. Through these human, habitual biases, I have experienced ageism and ableism where clinicians may have felt that I lacked the intellectual capacity to appreciate the state of my health and my treatment options. I have also been spoken down to and even frequently asked why my mother was not present in clinical settings. Health care providers have also made assumptions about my physical capabilities because I use a wheelchair as my main method of mobility. My point is that the individual needs

of patients should be considered regardless of age, ability, gender or any other quality, rather than being based on the assumption of providers. In the paediatric system, there was such an emphasis on care providers talking to children and involving them in care planning to prepare them for adolescence and adulthood. It seems rather ironic that adult care is the reverse.

3. What could have been done differently to make the experience better for you?

At times, the abstract and grandiose goal of "making a difference" comes down to simple things, such as: making an attempt to ensure that patients don't feel rushed during the assessment/evaluation of care, fostering mutual respect, and attempting to appreciate the other person's perspective. These simple gestures can have a lasting impact.

The concepts of Quality Improvement and Evidence-Informed/Based Medicine are not simply a matter of gathering data or developing a checklist. They can also be seen as an iterative process with opportunities for dialogue, for example, by utilizing the elements within the quality improvement framework: patient-centered care, equity, efficiency, effectiveness, timeliness, and safety. The components within evidence-informed medicine include analyzing, translating and applying the evidence when developing, and disseminating clinical competencies and embedding these with the desires and preferences of the patient and their support system. We must be acutely aware of the constantly evolving needs of our communities. While wellness may be defined by the absence of illness in acute and episodic settings, for congenital and chronic conditions, wellness is more of a fluid concept, with an extending spectrum and ever-diversifying trajectory. My hope is that even as we are continuously in pursuit of clinical excellence and innovation, we must also maintain our passion for compassionate, patient- and family-centered care in nurturing the art of medicine.

Mining Unstructured Data to

Improve Health Care Transitions

By: Neil Seeman

Is there evidence that mining this vast array of unstructured data can positively influence health care? The short answer is "yes".

I In Ontario and across Canada, rich sources of health information remain largely untapped. I am referring to unstructured data, which I define as health information derived from non-research-based digitized sources. Examples include: written text in electronic health records, pharmaceutical prescription data, open text survey data, Facebook entries, Twitter feeds, blogs, web pages, online discussion forums and other similar sources of open source data that can provide insight into the health of Canadians and their subjective experience of the quality of our health care system.

Some of these data are entries by clinicians or administrators; others, the most valuable perhaps, are written in the patient's own voice. Online social networks have become popular platforms for people to interact with each other and discuss any number of topics, including

health and health system concerns. In this paper, I propose leveraging the use of unstructured data to better understand patients' and caregivers' experiences with transitions in care.

These unstructured data share three characteristics: volume (they are plentiful), velocity (they become available quickly but may also disappear quickly), and variety (they exist in many forms). They often lack a fourth "v," which is veracity – in other words, they are not necessarily accurate or 'evidence-based' (Martin-Sanchez & Verspoor, 2014; Normandeau, 2013). While validity may therefore be in doubt, these data unquestionably complement the more traditional sources of health information and patient experience (e.g., results of clinical trials, case reports, focus group or paper-based patient experience data).

All the traditional methods of gathering information reach their conclusions by studying relatively limited numbers of patients so that generalizability to a larger range of potential patients remains questionable. As the world dramatically shifts from paper to electronic formats, digital data offer a much larger evidence base. Leveraging such data to improve

health care quality, however, poses three challenges.

The first challenge is that the data exists in free-form text or, at best, semi-structured clinical documentation, dispersed among different providers, and in different social media. They are, thus, difficult to standardize, analyze, and aggregate. The second challenge is to glean worthwhile insights from this mass of texts even when it is organized, insight that can improve the quality of care, and, specifically, transitions of care.

In this article, I offer a path forward toward solving these two challenges. I suggest that we bring the Ontario health care start-up and institutional communities together to 'hack our way forward', as I explain in the conclusion. This requires overcoming the third challenge, which is to ensure privacy (Kum & Ahalt, 2013). We are talking about data that should enjoy the same legislated privacy protections as do, for example, patient health records. Unstructured data are often tagged with personal identifiers, and therefore, are fraught with privacy challenges. This is a thorny problem and constitutes one of the critical barriers to the full use of these rich data sources.

Return-on-Investment? Show Me the Evidence

Is there evidence that mining this vast array of unstructured data can positively influence health care? The short answer is "yes".

One example is epidemic surveillance. In 2012, Young and colleagues collected more than half a billion tweets and found almost 10,000 that mentioned sexual behaviours and drug use which are risk factors for HIV infection. By placing the geographic origin of these tweets onto a map of the world, potential hot spots for HIV could be discerned, showing how social media can be used to monitor the spread of infectious disease (Young, Rivers & Lewis, 2014). In the same vein, geographic comparisons can be made to assess within which regions patients experience transitions across the continuum of care that are coherent and linked, or experiences of overt or subtle discrimination during such transitions.

As evident in this example, security and privacy risks need to be addressed: even if the data are anonymized and are not traceable to individuals, there should be no way for anyone to be able to know whether particular, identifiable sub-populations in a community are disproportionately at risk for HIV. It is critical to prevent bringing attention, stigma, and discrimination to a population already at risk.

In my view, transitions in care are places where the use of unstructured data can be especially useful, especially since very few tools exist that comprehensively measure patient experience across transitions. Despite this, transitions are crucial points in health care delivery which can impact patient outcomes and the quality of care provided. Transitions are difficult for patients no matter what their illness – first, the transition from well to ill, then the various stages of navigating the health system: accessing help, waiting for referrals, admission to hospital, discharge to home or to a rehabilitation service, home care, or transitioning across the

paediatric/adult/geriatric frontiers. These all constitute periods of stress and unmet need often expressively voiced in Facebook entries or in personal blogs that, once organized and analyzed, and safely (i.e., personal identity removed) disseminated, have the potential to provide valuable information that might help to improve the experience of patients as they transition across the continuum of care.

Figuring out how to best leverage unstructured data for any return-on-investment is neither a human resource challenge nor a technology challenge, but a strategic one. Essentially, the issue boils down to improving the quality and subjective experience of transitions in health care within Ontario while preserving the privacy of patient data and guaranteeing their secure storage.

Meeting the First Challenge: Finding the Relevant Data

Since unstructured data exist in so many different forms, the first challenge is to find in a very large haystack the needles of data that are germane to improving transitions in health care. This first step involves drawing on expert stakeholders' input to define more precisely what the problem is we are trying to solve. Are we trying to better understand the experience of transitions of care from the perspective of the patient? Are we trying to fill the gap of unmet needs of patients, families, providers,

> **Figuring out how to best leverage unstructured data for any return-on-investment is neither a human resource challenge nor a technology challenge, but a strategic one.**
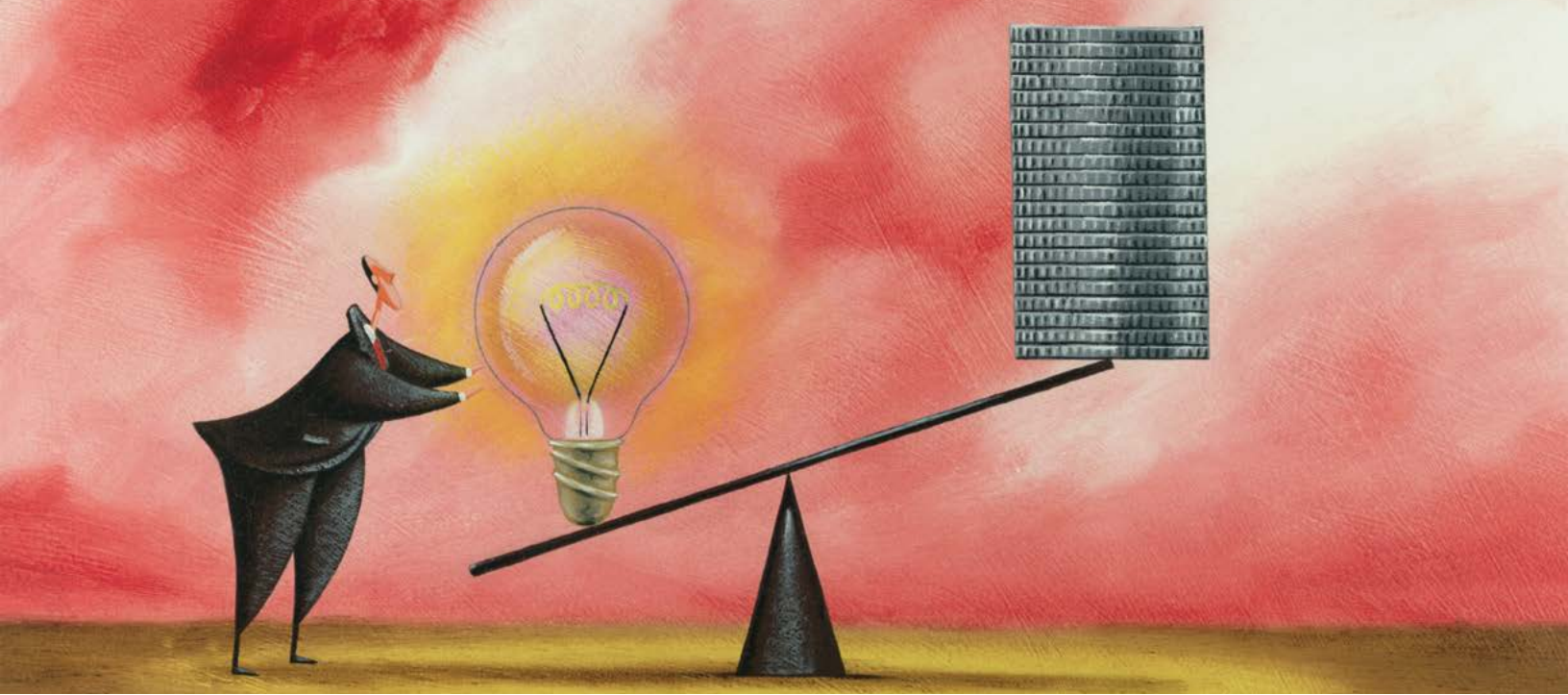
or all of these groups? Are we trying to minimize costs, to reduce lawsuits? Is our aim to ensure that patients and families continue to be treated with respect and with skill during care transitions? Is this an attempt at quality improvement?

Depending on the answers to these questions, different forms of unstructured text can be targeted. For example, improving the experience of transitions may involve the use of open text narratives on Twitter to assess the degree to which patients or caregivers express increasing or decreasing frustration online about access points, or parking lot capacity, wheelchair availability, or failures by care providers to transmit important clinical information.

Alternatively, if the goal of the initiative, as defined by expert stakeholders, is to identify the best practices of those most skilled at transitions of care, we may wish to engage in natural language processing of open text comments and online reports that refer to a range of providers and link the most publicly favored among them to clusters of health care facilities in a certain

geographic region. We can ensure privacy by excluding identifying remarks and aggregating the data. We can then dig deeper to discover if the preferred provider group shares critical characteristics. Have they adopted a particular model of care that focuses on improving care transitions? Were they trained under the same clinical mentors? What other factors distinguish them?

Relevance to a chosen topic should involve an expert panel consisting not only of patients, caregivers and providers, but also of information technologists who can provide guidance as to methods of extraction by searching for key words, creating a coding scheme, systematically applying the codes to the selected documents, testing for inter-coder reliability, counting the numbers of codes for each document, and analyzing the counts by a variety of statistical methods (Bernard, 2012).

Natural language processing (NLP), which means using heavy computing power to make sense of the semantic or representational meanings hidden in extraordinarily large data sets, is then able to

extract relevant transition themes (such as communication across settings and among disciplines and specialties, family input into decisions, cross site co-ordination, the inter-disciplinary nature of care, access to required medications in an uninterrupted way, availability of appropriate transport between settings, anticipation of needs over the evolution of an illness, the efficacy of interoperable electronic health records, maintenance of a safety net throughout life, or education in patient self-management).

This has not yet been done specifically to search for subjective experiences across care transitions, but it has been done to better understand reactions to the general category to which transitions belong, the category of unexpected stressful events (Gaspar, Pedro, Panagistopoulos & Seibt, 2016).

Traditionally, care transitions have been studied through personal interviews or focus groups, mainly of professionals (Davis, Devoe, Kansagara, Nicolaidis & Englander, 2012; Gott, Ingleton, Bennett & Gardines, 2011; Greysen et al., 2014),

although patient voices have also been elicited (Pollack et al., 2016). In order to attempt to identify solutions to care transition problems, Lim, Jarvenpaa and Lanham (2015) reviewed published qualitative studies and came to the conclusion that time pressures were at the heart of many of the reported difficulties. While, as stated above, transitions have not yet been specifically researched on social media, public health questions on a range of topics are beginning to be profitably addressed by mining this rich source of data (Ji, Chum, Wei & Geller, 2015).

Meeting the Second Challenge: Elegant Organization and Operationalization

Organizing the wealth of unstructured data that can be obtained from various sources remains a major challenge. Advances in computer science, such as virtualization and cloud computing have made it possible to accommodate, link, and analyze large, diverse data sets (Raghupathi & Raghupathi, 2014). This requires a staged process by which the information from various sources initially needs to be pooled and distributed on open source platforms available in the cloud. Various statistical methods are used: cluster analysis, decision-tree learning, Bayesian networks, NLP, graph analytics, and other data visualization approaches. The best guidance is to learn from search engine leaders,

notably Google, whose leadership in Bayesian algorithms and PageRank analysis has pioneered the modern Internet to guide us in identifying what information is trusted, and what information is not.

Solving this is beyond the scope of any one health care institution, and, as such, I recommend first using free tools made available by Google itself. Public datasets can be analyzed for free in the Google Cloud platform (https://cloud.google.com/public-datasets/). Boolean search strings plugged into Google search, e.g., 'free data sets' AND genes, or 'free data sets' AND 'Ontario' AND 'health care', are a good start. After the data sets are found, a novice unstructured data researcher can insert them into the Google platform. One first searches for correlations and emerging patterns. Predictions can be made from repeating patterns.

The challenge of establishing the veracity of the information requires technology and systematic analysis by experienced researchers. A large variety of methodologies are available

for data integration and resolution of inconsistency among data sets (Gray & Thorpe, 2015; Neff, 2013).

Unstructured Data in the Context of Broader Data Needs

In order to improve standards for care transitions and increase the quality of care generally, there is another, higher level of analysis – informed by principles of equity and prioritization of need – that points out questions that require the most urgent attention from a data gaps perspective (Golden, Hager, Gould, Mathioudakis & Pronovost, 2017).

We need to understand the human impact of care transitions on patients, families and social networks; we need to know their economic impact on the health care system in terms of job satisfaction, health service costs, pharmaceutical costs, and costs to the legal system. We need to be able

We need to understand the human impact of care transitions on patients, families and social networks; we need to know their economic impact on the health care system in terms of job satisfaction, health service costs, pharmaceutical costs, and costs to the legal system.

to identify best practices (Naylor et al., 2017), to determine the role of family physicians, the distinctive role of the many health professionals involved in care transitions, the role, if any, of paraprofessionals and alternative care providers. We also need to be aware of obstacles to smooth transitions – currently thought to be time pressures, faulty communication, fragmentation of services and inadequate staff training.

One way to evaluate what we do in Ontario is to analyze data from around the globe as they pertain to transitions – compare successes and failures and costs, and specific regional challenges to determine how we might be able to do things better. Unstructured data lend themselves to such comparisons.

Recent Progress

Seven years ago, on behalf of The Change Foundation, I helped to write a report titled, *Using Social Media to Improve Health Care Quality,* in which we identified the fact that the vast majority of North American health care organizations were not taking advantage of social media data (i.e., the most commonplace form of open source unstructured data), and thus were neglecting a source of patient-driven information (e.g., complaints, expressions of unmet needs) that could, if accessed, potentially lead to insights for quality improvement (The Change Foundation, 2011).

Some progress has been made since then, as described above, but probably not enough. Privacy issues have remained barriers. How

much we can rely on the validity of unstructured data is an unanswered question. Numerous bodies, including institution-specific research ethics bodies, are investigating both of these challenges.

Since global public health (notably in the field of pandemic surveillance) has seen some of the earliest usages of unstructured data on a global scale, it is not surprising that organizations such as the Global Public Health Intelligence Network (GPHIN) and the Public Health Agency of Canada (PHAC) are setting forth ethical frameworks and publishing thought leadership to address evolving paradigms in the ethics and privacy needs associated with the use of unstructured data for health care quality generally (Public Health Agency of Canada, 2015).

The broader framework of 'Privacy by Design' (PbD) developed over a decade ago by the Information and Privacy Commissioner of Ontario should, in the author's opinion, guide all application discussions (Cavoukian, 2009). The PbD principle of application "with special vigour to sensitive data such as medical information" is important; however, in the author's view, there is a critical amplification that should be stressed in the context of the unstructured data referred to in this article. That is, in the context of the application of unstructured data to solving transitions-related policy issues, PbD should, in the author's view, be applied with special vigour to sensitive data that is prone to misinformation.

In other words, the challenge of veracity in the use of unstructured data, referred to earlier, is inseparable from the challenge of data privacy.

Privacy and security are insufficient; the data have to be accurate.

Hacking a Path Forward

I recommend an Ontario-wide sponsorship of a 'hackathon' – a community of individuals bound by a common and novel mission, in this case, refining the obstacles to using unstructured data to promote aspects of health care quality. Already, the Ontario start-up community has a vested interest and desire to participate. Ontario enjoys a diverse and passionate start-up community developing mobile health apps, and advancing health care data visualization and data mining. Many of these start-ups have faced challenges monetizing their platforms and understanding the needs of potential customers and partners. To address all such problems, it would be strategic to bring together the people most passionate and motivated to solve them; solutions could then be shared. This is a low-cost first start to what may be a very high return on investment for the Ontario health care system.

Many research teams are working on mining unstructured data, with varied success. This is a growing trend in other industries, and health care would stand to benefit greatly from this rich source of data which can present new opportunities for improving care perhaps, never before considered. Doing it well can lead to increased knowledge, decreased obstacles to the receipt of high-quality care, and lowered costs, both human and economic.

Individual practitioners, clinics, and hospitals need to heed what is being said about them and their personnel on online service rating sites. These anonymous criticisms, when taken seriously, can lead to local quality improvement without necessitating large-scale data mining. On a larger scale, only an expert group, sensitive to overarching priorities in the sector of interest and their own institutional priorities, can begin to identify the strategic demands most in need of unstructured data. Along this journey, technologists who are expert in NLP and other machine learning processes can lend guidance to the art of the possible, but should not, of course, be permitted to drive the setting of priorities.

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About RIWI Corp.

RIWI Corp. (www.riwi.com) is a global survey, global messaging and global prediction science firm that has collected opinion data, machine data and unstructured data from more than 1.2 billion web users in every country and territory of the world for organizations such as the United Nations World Food Programme, the World Bank, the Bill and Melinda Gates Foundation, the U.S. State Department, Freedom House, and governments and corporations around the world.

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The Missing Peace in End-of-Life Care

Anthony Dale, President and CEO, Ontario Hospital Association

In the spring of 2014, my family received life-changing news that our father, John, had cancer once again after undergoing a successful surgery only 18 months prior – and the prognosis was poor. Unfortunately, the news was delivered by a cancer specialist in a terse, detached manner – a theme that would be repeated as our family continued to navigate the health care system.

In contrast, our initial encounter with the system, when the cancer surgery was performed, went smoothly. John had received high-quality care, as expected. However, once it was determined that the cancer had spread and surgery was no longer an option, he suddenly moved into a "blank zone". Absolutely no one stepped forward to advise about what to do next, what resources or supports were available, and, most importantly, to discuss his end-of-life wishes. Navigating the system and advocating for our father was left to our family as our sole responsibility.

While the system excelled at providing traditional, episodic care, as soon as my father's care fell outside these parameters, his experience and ours, as his caregivers, suffered.

The gaps in care along the way were evident. Because my father received acute care outside of the community in which he lived, home and community care supports were exceedingly difficult to coordinate. Communication was sporadic, and often times, we had to pursue providers for follow-up and direction. My father's wishes were not considered, and even as his health deteriorated, surprisingly, no assessment for palliative care support was made available.

Ultimately, a crisis triggered his admission to a hospital where he was treated to ease his pain. Unfortunately, he passed away quickly in his hospital bed shortly after receiving treatment, in a room he had shared with another patient. It was exactly the place he did not want to be. My father had wanted to die at home, surrounded by his family.

We tried our best to make arrangements in order to fulfill his request. However, because of how quickly his health had declined, the inherent gaps in the system and the various barriers we faced while trying to coordinate the

home and community supports required for palliative care, his dying wish was not met.

Looking back at the most trying times we have ever gone through as a family and the helplessness that we had all felt, I still consider my family among the luckier ones because of the support we were able to lend our father at his time of greatest need. However, it was still a shocking experience.

While there were pockets of care that were excellent, the experience as a whole was disjointed.

Siloed thinking seemed to be present both at the individual and system level – no one considered my father's broader needs or tried to weave together the various aspects of his care. Instead, people focused only on his immediate needs as defined within their narrow scope of responsibility.

Families and caregivers should not be left alone with the heavy burden of advocating for care and navigating the system while dealing with the emotional turmoil of tending to an ailing family member.

As a system, we need to ensure that receiving care is not an uphill climb. This means acknowledging that innovation and real investments are needed across the continuum, especially in the home and community care sector and in palliative and hospice care. Equally critical is making a genuine and concerted effort to establish care plans based on an individual's unique needs and grounded in preserving a patient's dignity.

My personal experience has taught me that we must act decisively, selflessly and courageously so that patients and their families can have peace of mind knowing that the right kind of care is available for them no matter where they are in their health care journey.

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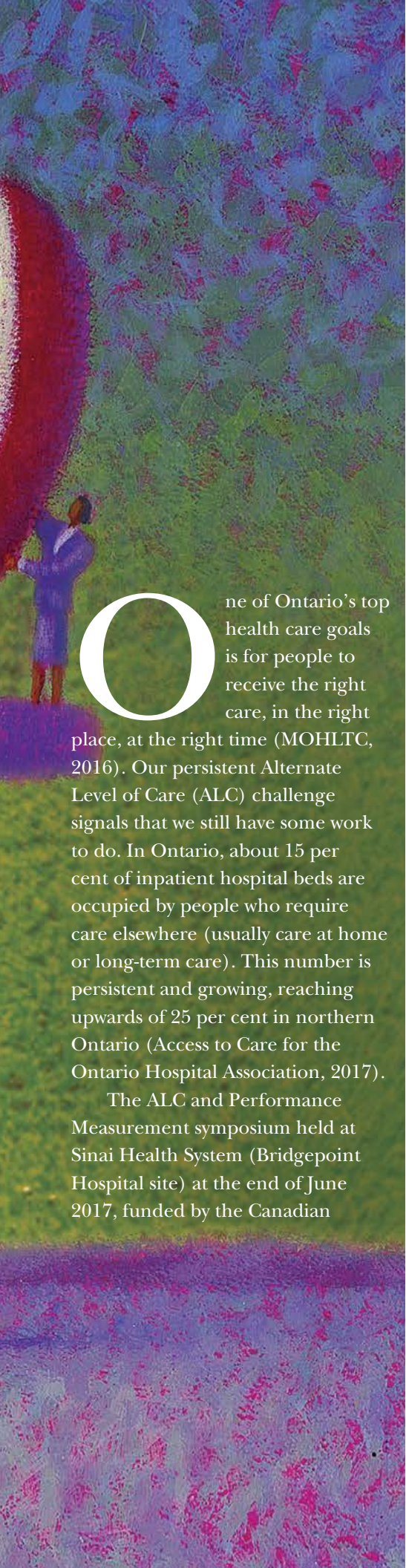| Call	416 205 1354
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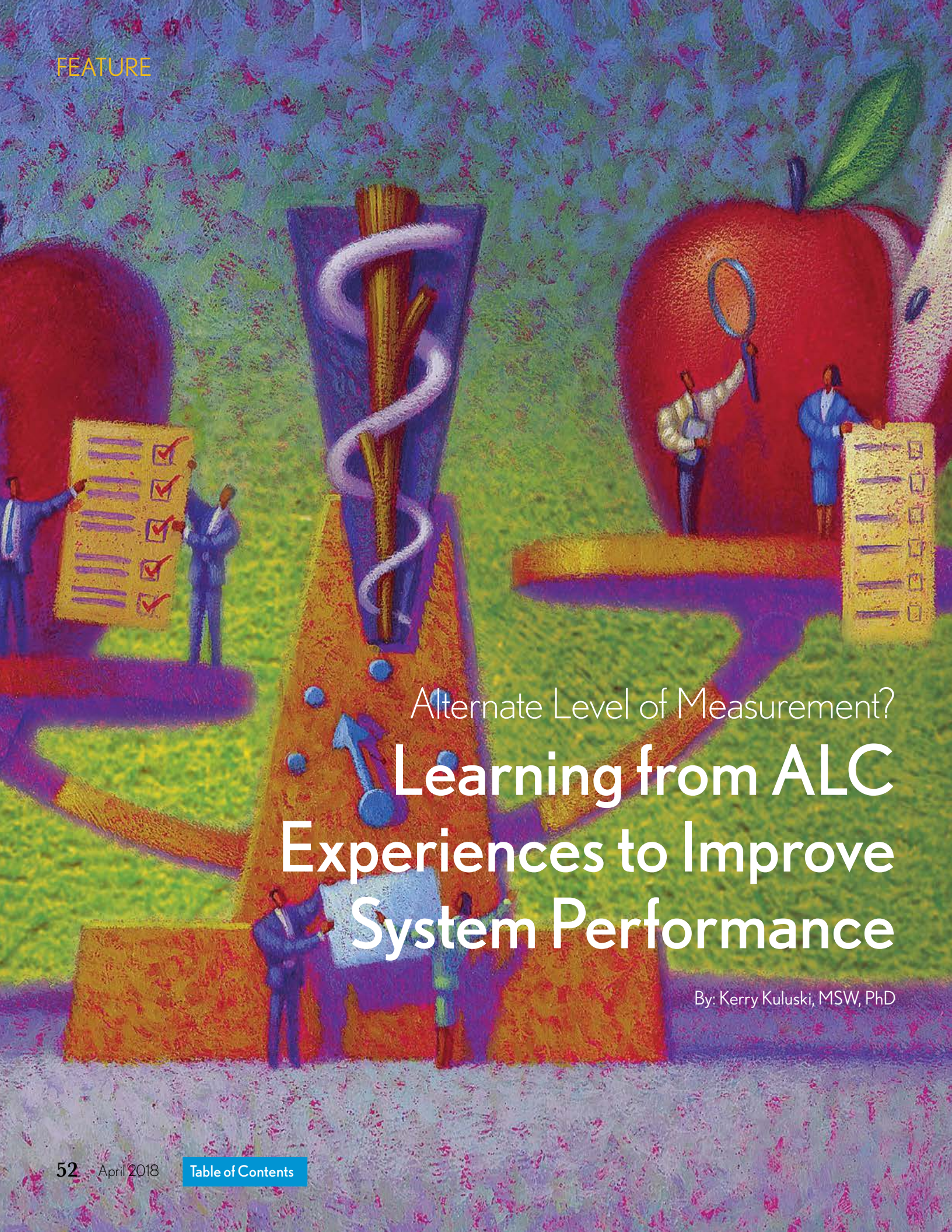
Alternate Level of Measurement?

Learning from ALC Experiences to Improve System Performance

By: Kerry Kuluski, MSW, PhD

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Developing a holistic view of patients, rather than limiting this view to a single point in time, is necessary if we are to effectively address the ALC challenge.

One of Ontario's top health care goals is for people to receive the right care, in the right place, at the right time (MOHLTC, 2016). Our persistent Alternate Level of Care (ALC) challenge signals that we still have some work to do. In Ontario, about 15 per cent of inpatient hospital beds are occupied by people who require care elsewhere (usually care at home or long-term care). This number is persistent and growing, reaching upwards of 25 per cent in northern Ontario (Access to Care for the Ontario Hospital Association, 2017).

The ALC and Performance Measurement symposium held at Sinai Health System (Bridgepoint Hospital site) at the end of June 2017, funded by the Canadian Institutes of Health Research, provided a forum for stakeholders – providers, policy planners, patients, caregivers and data developers – to reflect on future directions to address ALC with a strong focus on measurement and personal care experiences.

At this symposium, Professor Jon Glasby, Head of the School of Social Policy at the University of Birmingham, referred to ALC as the "deep hospital". It refers to a phenomenon observed by those in the field: the deeper – or perhaps longer – a patient is in hospital, the harder it is to get out. What can we do to avoid the deep hospital?

As a start, we can look at the data we currently have to better understand the problem. In Ontario, Cancer Care Ontario's Access to Care branch provides real-time ALC data, including the numbers and care destinations of all ALC patients in acute and post-acute hospitals across the province. This data resource provides a huge opportunity for Ontario's health system to address the issue and develop a capacity plan. However, to truly understand how to build capacity in the system in a way that works for people, we need to marry these data with people's stories, particularly the stories of people in the trenches of ALC: patients, their families and providers. Capturing their stories may point us toward person-centred solutions to the ALC challenge, which is another goal of Ontario's health system with the passage of the *Patients First Act (2016)*.

Capturing Missed Opportunities to Intervene

At a health system level, we tend not to measure experience across settings or take into account the rather complicated, messy, cumulative or longitudinal experience of patients and caregivers. Despite its messiness, gaining a snapshot, over time, of this experience will help us see and understand these individuals within a broader context. Capturing this broader context is vital to identifying solutions to the ALC challenge that will work in the longer-term.

Using a hospital admission as an example, we can ask: "What were the events leading up to the person's hospitalization? Why do they return to the hospital? What are the barriers to staying at home? How can we make it easier for the person and their caregiver in their day-to-day activities?"

While some organizations are already asking these questions, we still need a population-level stock of answers to these questions to make a stronger case for future health reforms. These questions will likely lead us outside the confines of the health care system and necessitate relationships with other sectors, such as housing, finance, transportation, and other community supports. They also inevitably bring us to the whole notion of prevention. Professor Glasby's research revealed that there were missed opportunities to intervene in the period of time before hospitalization that could have potentially made a difference with respect to prevention (Glasby & Littlechild, 2016).

Developing a holistic view of patients, rather than limiting this view to a single point in time, is necessary if we are to effectively address the ALC challenge. What we've learned so far from patients' experiences and Professor Glasby's research is that isolated initiatives are insufficient responses to such a complex issue. Any effective solution will take time, decisive action and collaboration across the system.

Measuring What Really Matters

Understanding patients' view of quality is essential to developing a performance measurement strategy and appropriate metrics that reflect this view. Measurement tools have pre-conceived assumptions of the things that shape a patient's experience and may (by virtue of the questions asked), miss aspects of experience that are important to people, and specifically in this discussion, contributors to the ALC challenge. While current measures tap into important elements of experience like the relational aspects of care (e.g., were you treated with respect and dignity?), we need to look beyond these elements.

The needs and priorities of patients and caregivers might not have anything to do with a particular health care service, a relationship they have with a provider, or a particular disease or symptom. Asking, "What are your goals?" and "What are you most afraid of?" could signpost where people's needs may be greatest. Post-discharge questions, such as, "Were you confused?" and "Were you given a number to call; if so, was it helpful?" are other questions that would signal communication breakdown, poor access to resources, and other areas that need attention.

The growing challenges with ALC can be viewed as symptomatic of a greater problem within the system as whole. By measuring what really matters to patients and caregivers, we have a better chance of arriving at the root of patients'

health care challenges. This, in turn, will help us identify what supports we can put in place as a system to enable more seamless care across the continuum, effectively address current patient and caregiver needs and ultimately reduce ALC.

Considering the Voice of Caregivers – Paid and Unpaid

Another critical consideration in any measurement and action strategy is to understand health outcomes, experiences, and costs for all types of care providers (both paid and unpaid).

When patients enter the system, do we document if they have a caregiver and what their capacity to care is? Do we consider how we can best support them (now and when the person they care for returns home)?

Unpaid family members and friends play a crucial role at all stages of the patient's illness, including care of the patient during the ALC phase (Kuluski, Im, & McGeown, 2017), and therefore, are an integral aspect of solving the ALC challenge. Moving past ALC and into post-discharge care is highly contingent on a caregiver's willingness and availability to continue to provide care and support. Ironically, they may be left out of relevant discussions (Jeffs et al., 2017).

Caregivers need to be formally identified, as they themselves may not call themselves, or recognize themselves, as caregivers. Caregivers

may have important questions about how to provide care (which can include heavy personal care), and how to seek supports for self-care. Caregivers often suffer from heath consequences (they can become patients) and endure large sums of out-of-pocket and opportunity costs. Greater understanding of how caregivers fit into patients' health care journeys cannot be overlooked if we are to effectively address the ALC issue. Providers can use this information to develop better supports for caregivers and also optimize the way the system interacts with them to enhance patient outcomes.

These strategies must be coupled with support for paid care providers. Similarly, we must ask, "How can paid providers be supported in their role to capture the patient and caregiver story and be resourced to respond?" It is easy to criticize the decisions and practice patterns of providers when we don't consider the busy and unpredictable contexts in which they work, which leaves little time for important conversations with patients and families.

Taking a Comprehensive View

The patient and caregiver voice can lend greater depth and understanding to a complex problem such as ALC. In attempting to capture their experiences and perspectives, we need to ensure that we are asking the right questions, and taking a more comprehensive view of their circumstances which can impact their health, their ability to recover or maintain their health, and inevitably, their health outcomes.

In a system that is struggling with capacity issues due, in part, to an aging and growing population, we need to consider marrying people's lived experience with quantitative data, and perhaps we can introduce more thoughtful and enduring solutions to a long-standing challenge.

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Through the Eyes of Patients and Caregivers: Jeannie Faubert

Redefining Health Care spoke to a number of former patients and caregivers to ask for their view about care transitions.

Jeannie is a retired elementary school teacher. She is a Patient and Family Advisor (PFA) at Thunder Bay Regional Health Sciences Centre (TBRHSC), which has been granted a Leading Practice Award in Patient Family Centred Care by Accreditation Canada, volunteers at the TBRHSC emergency department doing patient surveys, and is involved with various patient advisor initiatives. Jeannie continues to be inspired by the commitment of TBRHSC, and enjoys the many rewarding opportunities she has had as a PFA to contribute to quality improvement efforts in hospitals and research efforts in health care.

1. Can you describe an experience when you transitioned from one health care setting to another?

My father-in-law, Jerry, had a hemorrhagic stroke. He was transitioned from our acute care hospital to the regional stroke rehab unit. He was 79 years old. At that time, I had already been a patient/family advisor at the acute care hospital, and was well-versed in the patient- and family-centred care approach.

2. Can you reflect on how your transition impacted you and/or your caregiver?

Due to the timing of the transfer, Jerry was never oriented to the new ward nor was the family. We had no idea about meals, policies regarding physiotherapy, speech or occupational therapy assessments and programming, nor that there were laundry facilities in house for families to access. We felt that this information should have been shared via a tour, or at least, some kind of patient/family information paperwork.

In contrast, at the acute care hospital, we always knew what was on the daily schedule and who was looking after Jerry in terms of nursing because of the use of the white board.

It was a transparent system that worked well. At the rehabilitation facility, there was minimal communication with us – the family – or the patient. We also observed that physiotherapy schedules were not adhered to as announced on their boards. To go from feeling informed to being uninformed, raises anxiety needlessly.

As well, during the transition from one provider to another, I felt that we were not involved or consulted in the discussion. We were basically informed that when Jerry was in safe condition, he would be transferred from the acute care hospital to the special stroke rehab unit.

Looking back, we felt that there was no continuity of care between the two facilities. It was as if each organization was not particularly concerned about the care Jerry received outside of their facility, as long as they did the job they were supposed to do. In short, there was a lack of continuity between the two facilities about how patients were communicated with and treated, so we were left to adjust to each organization's way of doing things, rather than them meeting our expectations and needs using a more standardized approach.

3. What could have been done differently to make the experience better for you?

I feel that there should have been more of an orientation to specialty wards for patients/families. Someone at the receiving facility should have to sign off on this when a patient is admitted. In the same vein, facilities need to have similar, consistently used methods of communication with patients or families (e.g., white boards with an expectation and commitment to use them). Doing so would improve the process considerably, particularly in a community where facilities are working together regularly.

I also later learned that the rehabilitation hospital has a patient and family advisory council (PFAC). I discovered that the PFAC was not easy to join and had more staff than actual patient/family advisors. Membership was closed, meaning that at the time, they were not recruiting any new members. Members were also only accepted from certain practice areas (e.g., mental health services, chronic disease management). From my perspective, it seemed as though the PFAC was not empowered and set up to make meaningful changes that would support and improve the patient and family experience.

I had ideas for improvement, but I found it difficult to find someone who would listen.

We also feel that the organization could have done a much better job at addressing our complaints and needs. Instead, we felt as though we needed to take exceptional measures to have our needs heard. Interestingly, this experience was very different from the acute care facility where we felt that patient and family engagement was sincerely adhered to, and in fact, was part of the strategic plan.

I hope that patients and their families can come to expect standard treatment across the system, regardless of facility. I would also like to see a more universal desire to involve patients, listen to their concerns, and provide them with a more consistent experience, no matter where they are receiving care.

International Perspective:

Investigating ALC through Patients' Lived Experience

Q&A

with Dr. Jon Glasby,
Professor of Health and Social Care and Head of the School of Social Policy, University of Birmingham, U.K.

In June 2017, Professor Jon Glasby was the keynote speaker at the Ontario Hospital Association (OHA) conference entitled, "Alternate Level of Care: Capacity Solutions and Practical Approaches." Alternate Level of Care (ALC) is a designation for patients who experience a delayed discharge because they are waiting for a more appropriate level of care. Professor Glasby's work underscores the importance of drawing on the tacit knowledge of people with lived experiences – including patients, caregivers and frontline professionals – to better understand and solve issues at stake, including delayed transitions and transitions in and out of hospital. We interviewed Professor Glasby to learn more about his research and how he has captured the voices of patients, caregivers and health care professionals to improve patient experience across the continuum of care.

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Q **Can you tell us what you have learned about transitions of care through your research with service users and staff?**

JG | In 2012, we carried out a study entitled, "Understanding and improving transitions of older people: a user and care centered approach", that involved in-depth narrative interviews with older service users and caregivers. We learned from them that care transitions involve far more than a move across services or settings. Participants in this study experienced transitions on a number of different levels:

1. Physical, including bodily changes as well as use of services;

2. Psychological, with changes in their identity or sense of self; and

3. Social, with changes in their relationships with partners, family and friends.

These different transitions often happened simultaneously, and if circumstances made coping difficult in one type of transition, then it was likely to have an effect on others. We found that while the physical aspects of transition are often a priority for service providers, the importance of the psychological and social aspects was frequently overlooked.

Between 2014-16, we carried out national research entitled, "Who knows best? Older people's contribution to understanding and preventing avoidable hospital admissions," where we set out to understand the appropriateness of hospital admissions for older people. We looked at the issue from the perspective of health and social care professionals, older people with recent experience of emergency hospital admission, general practitioners and hospital-based doctors, as well as multidisciplinary focus groups. We conducted this research because with an aging population and with pressures mounting on acute care, emergency hospital admissions of older people has become a key policy issue and the subject of significant media debate in the U.K.

What we found was that, in our sample, most older people were admitted to hospital appropriately according to system standards. However, these patients provided fascinating detail, and they often had a more sophisticated notion of preventing admissions than service providers.

For example, we learned from them that even if an admission was 'appropriate' (i.e., needed on that given day), there may still have been opportunities and the capacity to do things differently at an earlier stage, which would have helped prevent someone's health from deteriorating into a crisis. These older patients thus distinguished between 'inappropriate' and 'preventable' admissions – in contrast to frontline staff (who, by definition, only came into contact with the person when they came through the front door on the day in question, often already sick or injured). Overall, older people had a more nuanced approach to the issue as many were able to identify earlier actions which might have prevented their admission altogether.

We found that while the physical aspects of transition are often a priority for service providers, the importance of the psychological and social aspects was frequently overlooked.

Although policy and the media often claim that we could reduce emergency admissions if we could care for frail older people more appropriately in the community, we found that the vast majority of our sample felt they needed to be in hospital (as did all participating general practitioners (GPs) and hospital doctors). It's possible that some people are admitted to hospital when they don't need the services provided there, but we didn't see this in our research. Indeed, many older people were doing everything they could to stay away from/out of hospital, possibly even jeopardizing their health by not seeking help sooner. Even though they identified some cultural and service changes that might lead to a more long-term, preventative approach in time, there were no quick fixes or easy answers. Policy-makers and health services hoping to dramatically reduce emergency admissions by setting up 'service X' or introducing 'intervention Y' might therefore be disappointed! None of the findings identify a single service that could be established or a discrete course of action that could resolve such

problems. It's more about a change in mindset which seeks to listen more attentively to older people, sees their needs more holistically and which is determined to 'get it right first time.'

Q **How have the results and learnings from your research been applied?**

JG | Our 2012 study provided a series of recommendations based on the lived experiences of older service users and their caregivers, for health and social care practices. There were four recommendations specific to better managing transitions:

1. People value and benefit from having one key person who can link them with other services and who is there to support them when they need it. For older people undergoing any type of transition, the nomination of a key person who will provide continuity of support and act as a link to other services would address many of the difficulties identified by older people in our study.

2. For older people with dementia and those with ongoing health difficulties, life involves continuous change. Service providers, therefore, need to see the management of difficulties as an ongoing process and should be flexible to respond to changing needs. If their role and responsibility only relates to a small part of that process, their own actions nevertheless need to be taken in the context of understanding the longer-term process.

3. Advance notification and preparation play a vital role in helping people to manage the emotional and practical aspects of transition, and to exercise some control over the process. Participants varied in their desire for involvement in decision making at times of transition, but all wanted to be kept informed about what the likely next stages of their care would be and the anticipated timeframe. Effective communication includes communication about uncertainty.

4. Closer integration of services – especially across health and social care – would have a considerable positive impact on older people's experiences of transitions. However, there remain significant barriers to closer joint working (not least a series of financial barriers and incentives based historically on single-agency approaches), and leadership at national, regional and local level is needed to overcome these.

People value and benefit from having one key person who can link them with other services and who is there to support them when they need it.

Sometimes, the issues at stake and the solutions proposed seemed to be 'someone else's problem' – with everyone else needing to do something different (rather than 'me' needing to do something different).

Overall, I hope we've started a debate about 'who knows best?' (the sub-title of our study). Understanding the experience of older people and their families, and of frontline staff, isn't an optional extra. It is a vital component to addressing this difficult challenge. Tackling emergency admissions is complex and multi-faceted, and only an equally nuanced and multi-faceted approach is going to help generate solutions.

Q **How does the NHS measure and use the patient and caregiver experience to find solutions to transition patients across the continuum more effectively?**

From our 2014-16 emergency admissions research, we drew up national good practice guidance (based on the experiences of older people and health professionals) and distributed this free of charge to all hospitals, Directors of Social Services and lead GPs in England, as well as produced a free training video (see below for further details).

For example, the guidance speaks to the need for hospitals to better collaborate with their community partners. Most health professionals talked about the role that community health services and social care could play in reducing the need for hospital admissions.

However, this could sometimes feel like a very 'hospital-centric' view, with the risk that we value partner agencies for what they can do for us, rather than as an important service in their own right with their own priorities, strengths and ways of working.

There was less sense in our interviews with staff as to how hospitals were systematically informing themselves, their staff and their patients of what community or voluntary sector alternatives exist, how they were supporting partners to achieve their own priorities and how the hospital might need to adapt its own practices.

JG | Like many health systems, most of our approaches have traditionally been single-agency in focus, making it difficult to understand how patients and their families experience the overall health and social care system, or transitions between services. However, a national coalition of patient charities, National Voices, has produced helpful work on defining the outcomes of integrated care from the perspective of people using services (known as the 'I statements' or a 'narrative for person-centred, coordinated care'). There has also been further work to look at how we might measure people's experiences of integrated care. While there is no single approach that could do this well at the moment (and

developing a new, bespoke approach would be expensive and difficult to implement), this work did make a series of practical suggestions for developing existing datasets and measures to help provide greater insight.

A more recent article in the *International Journal of Integrated Care* has also taken this on by developing a new survey tool to capture the experiences of older people with chronic conditions regarding how well their health and (where applicable) social care is coordinated. However, for me, this isn't a substitute for actually talking to and engaging with people using services, their families and frontline staff – maybe they have experiences and answers that our current measurement systems, tools and services do not tap into.

Q **What can other jurisdictions, like Ontario, take away from your research?**

JG | It sounds basic, but a key message from our research is that older adults and service users are experts by experience. No one else, no matter how well-trained or educated, can possibly have had the same experience of deteriorating health, trying to seek help and admission, the hospital stay and subsequent discharge. This is a critical source of expertise that we often overlook, but that we neglect at our peril.

For further details and resources on the emergency admissions study, see the following resources available on www.birmingham.ac.uk:
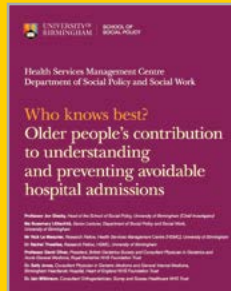
The full research report

A national good practice guide sent to all English hospitals, leads GPs and Directors of Social Services

View the free training video, *How older people can help understand & prevent avoidable hospital admissions,* on Youtube (published in 2016 by the Social Care Institute for Excellence).

A free training video hosted by the national Social Care Institute for Excellence (SCIE)

For further information on the transitions study, see: Ellins, J., Glasby, J., Tanner, D., McIver, S., Davidson, D. & Spence, K. (2012). *Understanding and improving transitions of older people: a user and carer centred approach*. Birmingham, Health Services Management Centre/National Institute for Health Research.

For further details, and a resource pack on working with service user co-researchers, visit: http://www.birmingham.ac.uk.