# How can we implement INTEGRATED CARE?



PRACTICE GUIDE SERIES

- 1/ How can organizations implement integrated care?
- 2/ How can we better understand and meet the needs of patients and caregivers?
- 3/ How can patient and caregiver needs be met by providers and managers?
- 4/ How can patient and caregiver needs be met by collaborative governance?

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#### FOREWORD

#### **Four practice guides for Ontario Health Teams**

The following four practice guides were prepared for Ontario Health Teams (OHTs). The guides are relevant for any group of providers and organizations aiming to implement a connected health care system centred around patients, families and caregivers. Each of the four guides focuses on a different aspect of a more connected and better integrated approach to care and has a slightly different emphasis and target audience. The guides can be read independently but achieving the overall implementation of OHTs will require attention to all dimensions presented.

The first guide focuses on essential aspects of implementation. It outlines key activities that are necessary at the organizational and interorganization levels and activities required of senior management across organizations in order to enable managers and providers to reorganize around patient and family/caregiver-centred care. The implementation of OHTs will not be successful unless organizations think differently about care and set parameters so that providers and managers realign their care to think across organizational lines to encompass the patient's journey. The primary audience for this guide is organizational leadership.

The second guide focuses on what it means for care to be centred around patients, families and caregivers and highlights 6 essential attributes of patient and family/caregiver-centred care. Two case vignettes are presented that characterize when a care system is well organized around a patient, and when the care system is fragmented. Achieving the well-coordinated system is a common thread that runs through all of the guides with specific mention in 3. This guide is central to the overall focus of Ontario Health Teams and is relevant to all leaders, providers, patients and the public.

The third guide focuses on the activities of providers and managers that are necessary to achieve patient and family/caregiver-centred care. The activities are organized around the 6 attributes and specific vignettes are provided that demonstrate what providers and managers have to do to enable the well-organized system in contrast to the fragmented case. The audience for this guide is primarily providers and managers though it is relevant to senior leadership that need to create the context that enables providers and managers to focus on these new activities and to create the space and time required for change.

The fourth guide focuses on governance. This guide outlines the internal and external changes that have to occur to create sustainable systems of connected care. The audience for this guide is organizational leadership and governors.

While there are many important aspects to implementing integrated care, this starter set provides a basis for understanding important new ways of working and fundamental shifts in collaboration across health and social care providers. Many more topics are important including population-based management, co-design, human resources and workforce transformation to name just a few. The most important guidance is to retain a focus on what is important to patients and caregivers; gather together the people you need to work with; agree to a common vision and principles that support your planning and implementation work; and build and support trusting relationships with all your team members. These essential ingredients, blended with courageous action, will accelerate your success.



#### 1 practice guide summary

#### How can organizations implement integrated care?

In this practice guide, we review lessons learned in implementing integrated care in Canada and other countries and offer some guidance for leaders and boards on change management strategies.

#### What are the steps involved?

Reviews of experience elsewhere have outlined four phases in the development of integrated care:

- 1/ Initiative and design phase
- 2/ Experimental and execution phase
- 3/ Expansion and monitoring phase
- 4/ Consolidation and transformation phase

Success in moving forward through these four stages rests on a number of critical success factors, including a compelling common vision for improving care for specific populations, trust and collaboration among key stakeholders, strong clinical engagement, effective care coordination, well-designed care protocols, care coordination and follow up, involvement of patients in the co-design of care, and ensuring staff possess appropriate skills and expertise. Leaders must make long-term commitments to a shared vision and common principles.

- Leaders must recognize that the changes required for successful integrated care are not just technical (e.g., new information systems or new care protocols) but also adaptive (e.g., new relationships, new role and team assignments, and shared accountabilities for care and coordination). Adaptive changes require coaching and support, not just training.
- Change needs to be guided from the top, but led by front-line team members who understand the challenges of care delivery and coordination and whose experiences inform the design of new work flows, effective information and coordination strategies, and the maturation of new teams across agencies.

#### What are the 3 key takeaways?

The literature on integrated care includes a diverse set of models that have performed well, and a number of critical success factors are common to most of these models.



Critical issues in early stages of integrated care include the identification of target patient groups who will benefit from integrated care, the development of trusting relationships and agreements among service delivery partners, and the recruitment of clinical team members who have the competencies and support needed to test and refine new models of care.



Developing new information strategies to share clinical data, collaborate on care plans and coordinate activities facilitates better teamwork and better patient outcomes and experiences.

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# How can organizations IMPLEMENT INTEGRATED CARE?

#### INTRODUCTION

#### Why this is important

Designing and implementing integrated care requires collaboration across care delivery partners, including front-line clinicians, and program and organizational leaders. Lessons from international experiences highlight the key implementation activities, developmental milestones and critical success factors involved in effective integrated care. Implementation approaches using adaptive leadership styles that encourage engagement in service design and improvement will promote more effective designs and sustainability. This section provides an overview of integrated care and implementation strategies setting the groundwork for the more specific advice in the sections that follow.

#### Lessons from international experiences with integrated care

Integrated care is complex, involving multiple care interventions, new teams, increased communications among providers and greater coordination of care. Different approaches to integrated care have been undertaken in various countries, such as Accountable Care Organizations in the U.S., and Integrated Care Systems in England and Europe. Successful efforts in Canada have also been demonstrated. A variety of policy levers have been used to shape these integrated care efforts in different jurisdictions. The common denominator for these integrated care initiatives is the focus on improving outcomes for specific populations defined in terms of health status (e.g., frail elderly), disease groups (e.g., COPD, CHF, multi-morbid) or specific services (e.g., hip and knee surgery patients) (Nolte and McKee, 2008;

Nolte, 2017). Our guidance on the implementation of integrated care starts with understanding the key implementation activities involved and the characteristics of successful initiatives. Despite differences between models of integrated care, there are some common characteristics and similarities in the developmental paths for integrated care initiatives.

#### **How this relates to Ontario Health Teams**

The Ontario Ministry of Health and Long Term Care have outlined a Maturity Model for Ontario Health Teams (OHTs) that identifies the expectations for OHTs from initiation to maturity. The materials included here provide a more granular focus on critical issues based on the evidence base for integrated care.

#### INSIGHTS

#### **Key implementation activities**

Based on a literature search and expert review, Minkman and colleagues (2016) identified 9 clusters of activities that contribute to the development of integrated care. They labelled these clusters as: commitment, roles and tasks, inter-professional teamwork, delivery system, client-centredness, quality care, performance management, results-focused learning, and transparent entrepreneurship (see Figure 1). Minkman argues that integrated care initiatives follow a developmental pathway beginning with an initiation and design phase, an experiment and execution stage, an expansion and monitoring phase and a consolidation and transformation stage. These stages have been validated in other studies. The key implementation activities are listed in Table 1.

Development of integrated care can be grouped into four phases...

- 1/ Initiative and design
- 2/ Experiment and execution
- 3/ Expansion and monitoring
- 4/ Consolidation and transformation



#### Table 1/ Key implementation activities in the developmental model of integrated care

(Adapted from Minkman, 2016)

#### Phase 1/ Initiative and design

- Delivery system partners identify a targeted patient group and relevant services and care processes
- A multidisciplinary team designs a new care model for the targeted patient group
- Delivery system partners sign agreements to work together

#### Phase 2/ Experiment and execution

- New initiatives and projects are designed and tested to improve care for the target population
- Care protocols and pathways are developed based on the initial experience
- Care coordinators are embedded to facilitate navigation by patients and caregivers
- Information protocols are developed to exchange data on patients and their care and to facilitate collaboration among the team members
- New ways of working are tested to improve care and care coordination
- Evaluation metrics are used to assess the scale and impact of integrated care programs

#### Phase 3/ Expansion and monitoring

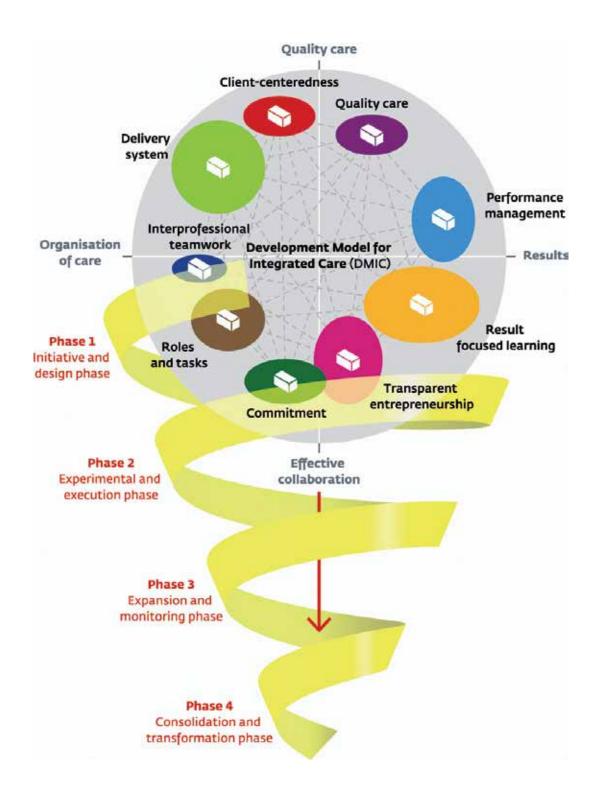
- Integrated care projects are expanded to new sites or patient groups
- Agreements on the content, tasks and roles of delivery system partners are revised and approved
- Outcomes, including patient experiences, are systematically monitored and used for improvement
- Delivery system partners examine interorganizational barriers and suboptimal financial arrangements to improve care delivery

#### Phase 4/ Consolidation and transformation

- > The integrated care program is no longer seen as a pilot, but rather the established way of delivering care to target patient groups
- Coordination has been extended across the continuum of care and information is shared on outcomes and experiences across sites and care delivery partners
- Performance monitoring provides ongoing results and informs improvement efforts
- Organizational structures are shifted to support the new integrated delivery processes
- > Financial agreements are shifted to support new care models and desired outcomes
- Care delivery partners seek new opportunities for collaboration with current or new partners.

Figure 1/ Development model of integrated care

(Minkman, 2016)



#### **Critical success factors**

In addition to the developmental phases of integrated care, a number of authors have identified critical success factors (see reference 1) for integrated care. These factors reflect leadership and contextual supports necessary for successful integrated care. This list of critical success factors is based on research on Accountable Care Organizations in the US, integrated care initiatives in the UK and Europe, and recent research on 3 successful integrated care efforts in Ontario undertaken by as part of a larger project examining integrated care in 3 jurisdictions. Table 2 lists these factors in 6 categories: leadership and governance, strategy and design, provider and manager activities, teamwork, funding and performance monitoring and improvement.

#### Table 2/ Critical success factors for integrated care

#### 1/ Leadership and governance

- Trust and collaboration established among key stakeholders in development of integrated care
- > Building on a history of successful partnerships
- Compelling vision for change especially around potential benefits for patients
- Transparency and communication among partners
- Partnerships that span a comprehensive range of social and community-based as well as healthcare services that specific populations require
- > Strong leadership and governance that is fully committed to clearly defined goals and helps to facilitate change
- Strong physician and other clinical leadership who support quality

- improvement and cost and help engage front-line staff in service redesign
- Create a strategic communications plan to provide clear messages to internal and external stakeholders
- Recognize that integrated care is a longterm agenda

#### 2/ Strategy and design

- Create a coherent strategy that incorporates the key implementation issues
- Identifying patient groups where benefits are greatest through population-based needs assessment (segmentation and stratification)
- Supporting clinician involvement in service planning, and implementation of new initiatives
- > Strong care coordination, embedded and/or linked to physician practices
- Restructuring care to deliver services in different sites/sectors
- Contracts or agreements with all participating partners (e.g., on data sharing, co-location of services)
- Geographic coverage to maximize access and reduce duplication of services

#### 3/ Provider and manager activities

- Following clear and consistent criteria to identify patients who will benefit from integrated community-based health and social care services
- Siving patients and caregivers opportunities to share what is most important to them in their care and including these preferences

- in individual care planning and decision making
- Involving patients and caregivers in service (co)-design and organizational decisionmaking processes
- Supporting and empowering patients to take control of their health (self-care)
- Using the workforce effectively and seeking innovations in skill mix and substitution
- Adopting standardized care protocols, pathways and care plans, adapted to local settings
- Identifying a single point of access for onboarding and assessing new patients
- > Ensuring effective flow and tracking of patient referrals (i.e. referrals are accepted, sent and followed up on, within your organization and across other organizations in the health and social care continuum)
- Regular patient follow-up and case management, particularly for the most complex patients
- > Facilitating transitions across care settings for patients and caregivers
- Addressing broader determinants of health that impact patient and caregiver's experiences
- Linking patients, families and/or caregivers to informational/educational and community resources
- > Ensuring case managers have appropriate skills and expertise to execute their roles
- Developing approaches to manage the cost of delivering integrated care services
- Promoting and supporting self-management practices

Ensuring that patients and caregivers have someone they can contact if health and social care needs arise

#### 4/ Teamwork

- > Building effective professional and interpersonal relationships with providers and other members of each individual patient's healthcare team
- Creating multidisciplinary provider teams with clearly defined roles and tasks
- Sharing patient information among providers
- Developing information strategies and technology such as EMRs and shared communications tools

#### 5/ Funding

 Funding mechanisms that promote teamwork and distribute resources to needed services

#### 6/ Performance monitoring and improvement

- Use a well-developed performance measurement and quality improvement system including feedback to physicians and other staff about results and performance accountability
- Supporting experimentation in design and delivery of collaborative, patient-centered care
- Continued and regular inter-organizational knowledge sharing
- Creating forums and opportunities for learning from external experts and organizations

#### **Change management strategies**

The list of critical success factors in Table 2 underlines the complexity of integrated care and the range of changes needed in developing new or expanded roles, expanding program and organizational supports, creating collaborations and improving teamwork and engaging patients and caregivers, clinicians and leaders. Successful integrated care initiatives require transformations at several different levels: between patients and providers; among inter-professional team members; and in developing strategies and approaches for communication and coordination among a network of agencies and organizations.

Nick Goodwin (2017), who has observed integrated care efforts in many different settings, argues that beyond specific activities, the change management

### The change management process should focus on...

#### 1/ Alignment

Supporting organizations to develop integrated care as part of their core business.

#### 2/ Agility

Developing systems and processes that support staff in implementing new care processes and enabling integration to happen at different levels.

#### 3/ Attitudes

Addressing the cultural changes needed to support new ways of working.

process must focus on 3 main goals: alignment, agility, and attitudes.

While each integrated partnership may vary somewhat in its developmental path, Goodwin suggests that success is dependent upon a long-term commitment from leaders to enable changes in work processes and relationships to mature and become embedded.

The developmental trajectory for integrated care initiatives is challenging since many of the critical changes are adaptive rather than technical (Heifetz and Linsky, 2002). While technical changes can be solved with the current skills and problemsolving methods within organizations, adaptive changes require learning new ways of working and, often, new skills for solving problems. Adaptive changes require not just new technology, but new approaches that require facing fundamental issues, in some cases they require rethinking how an organization or program works.

#### Front-line change

While change is necessary at all levels, the critical transformation to integrated care relies on changes in the work of front-line professionals with support from leaders to enable that change. This has several important implications for change strategies.

First it means that the rate of change is linked to the capabilities of staff (and engaged patients) to redesign care and learn new ways of working. In many cases, experienced and capable staff must learn to work differently, collaborating with staff in other programs or organizations, sharing responsibilities for patient care and support. Staff development and coaching, both in the technical skills required for their new tasks and roles, and in the adaptive process of adjusting to new challenges

can be critical to their success. This can be frustrating for leaders who want the pace of change to move more quickly. However, accelerating these changes depends upon supporting front-line staff in changing their behaviors and skills, not simply in pushing harder for change.

Thus, the second important implication of effective change strategies is that change has to be bottom-up as well as top-down. Staff need space to develop new approaches to care and collaboration, and support to innovate and adapt improvements. Many successful integrated care initiatives have found coaching resources, practice facilitation and quality improvement expertise essential to the development of integrated services. These resources and skills help to support change from the bottom-up and contribute to an environment supporting clinician engagement, a crucial success factor for integrated care.

Beyond specific skills for designing, coordinating and improving integrated care, Evans and colleagues (Evans et al., 2016) have identified 6 competencies for leading systems of integrated care for populations with complex care needs (see opposite).

## The six competencies for doing integrated care well are...

- 1/ Framing and reframing issues to create clarity, enable shared purpose and build consensus
- 2/ Taking the perspective of others to build trust and create safe spaces for collaboration
- 3/ Co-designing care with patients and caregivers to ensure systems provide care that meets patients' needs
- 4/ Systems thinking to optimize the performance of the system as a whole
- 5/ Sharing power to enable others to make decisions and act
- 6/ Reflective learning that enables learning from successes and failures

#### Three key takeaways

The literature on integrated care includes a <u>diverse set of models</u> that have performed well, and a number of <u>critical success factors</u> are common to most of these models.



Critical issues in early stages of integrated care include the identification of target patient groups who will benefit from integrated care, the development of trusting relationships and agreements among service delivery partners, and the recruitment of clinical team members who have the competencies and support needed to test and refine new models of care.

Developing <u>new information</u> strategies to share clinical data, collaborate on care plans and coordinate activities facilitates better teamwork and better patient outcomes and experiences.

#### EXERCISE: IDENTIFY PRIORITY ACTIVITIES

The guidance documents for Ontario Health Teams list multiple components that must be developed by those submitting proposals for OHTs (http://health.gov.on.ca/en/pro/programs/connectedcare/oht/docs/guidance\_doc\_en.pdf).

#### **Components for OHTs include:**

- 1/ Patient care and experience
- 2/ Patient partnership and community engagement
- 3/ Defined patient population
- **4/** In-scope services
- 5/ Leadership, accountability and governance
- 6/ Performance measurement, quality improvement and continuous learning
- 7/ Funding and incentive structure
- 8/ Digital health

The critical success factors for integrated care listed in this practice guide include a number of other relevant features that have contributed to the success of integrated care initiatives.

Using both of these lists, identify 3 specific priority activities for discussion and decisions for your organization and the partners engaged in your planning of integrated care.

#### REFERENCES

- 1/ Here we focus on organizational and partnership issues, not policy and funding considerations or clinical issues (e.g., polypharmacy or use of guidelines). Sources for this list include McClelland, et al., 2017; D'Aunnno, et al., 2018; Goodwin, 2017; Nolte, et. Al. 2016; and Threapleton, et al., 2017, Suter, et al., 2009; Ham and Walsh, 2013.
- 2/ D'Aunno T, Broffman L, Sparer M, Kumar SR. Factors that distinguish high-performing accountable care organizations in the Medicare shared savings program. Health Services Research 2018; 53(1):120-37.
- 3/ Evans JM, Daub S, Goldhar J, Wojtak A, Purbhoo D. Leading Integrated Health and Social Care Systems: Perspectives from Research and Practice. Healthcare Quarterly. 2016; 18(4):30-5.
- **4/** Goodwin N. Chapter 16: Change Management. Pp. 253-75 in: Amelung V, Stein V, Goodwin N, Balicer R, Nolte E, Suter E, editors. Handbook Integrated Care. Cham, Switzerland: Springer International Publishing. 2017.
- 5/ Ham C and Walsh N. Lessons from experience: Making integrated care happen at scale and pace. London, England: The King's Fund. 2013.
- **6/** Heifetz RA and Linsky M. Leadership on the line: staying alive through the dangers of leading. Boston, Mass.: Harvard Business School Press. 2002.
- 7/ McClellan M, Udayakumar K, Thoumi A, Gonzalez-Smith J, Kadakia K, Kurek N, Abdulmalik M, DarziSee AW. Improving Care And Lowering Costs: Evidence And Lessons From A Global Analysis Of Accountable Care Reforms. Health Affairs. 2017; 36(11):1920-7.

- 8/ Minkman M. The development model for integrated care: a validated tool for evaluation and development. Journal of Integrated Care. 2016; 24(1):38-52.
- 9/ Nolte E, Frolich A, Hildebrandt H, Pimperl A, Schulpen GJ, Vrijhoef HJM. Implementing integrated care: A synthesis of experiences in three European countries. Int J Care Coord. 2016; 19(1-2):5-19.
- 10/ Nolte E. Evidence Supporting Integrated Care. Pp. 25-38 in: Amelung V, Stein V, Goodwin N, Balicer R, Nolte E, Suter E, editors. Handbook Integrated Care. Cham, Switzerland: Springer International Publishing. 2017.
- 11/ Nolte E and McKee M. Integration and chronic care: A review. Pp. 64–91 in E. Nolte and M. McKee (Eds.), Caring for people with chronic conditions. A health system perspective. Maidenhead: Open University Press. 2008.
- 12/ Ontario Ministry of Health and Long Term Care. Ontario Health Teams: Guidance for Health Care Providers and Organizations. 2019; Toronto, ON. http://health.gov.on.ca/en/pro/programs/connectedcare/oht/docs/guidance\_doc\_en.pdf
- 13/ Suter E, Oelke ND, Adair CE, Armitage GD. Ten Key Principles for Successful Health Systems Integration. Healthcare Quarterly. 2009; 13(Sp):16-23.
- 14/ Threapleton DE, Chung RY, Wong SYS, Wong E, Chau P, Woo J, Chung VCH, Yeoh EK. Integrated care for older populations and its implementation facilitators and barriers: A rapid scoping review. Int J Qual Health Care. 2017; 29(3):327-34.





#### PRACTICE GUIDE SUMMARY

#### How can we better understand and meet the needs of patients and caregivers?

In this practice guide, we describe 2 key things: what matters to patients and caregivers and how to engage them in their care.

#### What matters to patients and caregivers?

Patients and caregivers told us that they want

- 1/ Be heard
- 2/ Have someone they can count on
- 3/ Know how to manage health and what to expect
- 4/ Easily access health and social care
- 5/ Be independent
- 6/ Feel safe

The practice document describes these things in greater detail, using the words of patients and caregivers.

#### How can we engage patients and caregivers in their care?

Patient and caregiver engagement in care is influenced by their:

- 1/ Perception of services
- 2/ Comfort in asking for things
- 3/ Beliefs about roles
- 4/ Access to resources

This practice document describes how to consider these barriers in practice.

#### What are the 3 key takeaways?



The things that matter most to patients and caregivers include relationships (how they feel when they interact with providers) as well as activities that make them feel human (hobbies), not just having medical needs addressed.



Taking the time to get to know patients and their caregivers will not only help them feel heard, it will help providers and teams understand the things that get in the way of them managing their health and participating in their care.



Activities to support selfmanagement of care needs to consider the context of the patient and family (where they live, their comfort in their surrounding community and accessibility to health and social activities) as well as their ability to access resources (finances, etc.) to supplement care.

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# How can we better understand and meet the needs of

# PATIENTS & CAREGIVERS?

#### INTRODUCTION

#### Why this is important

Efforts to improve care delivery and optimize experiences require understanding what is most important to people, particularly patients with complex health and social care needs and their family and friend caregivers. A precursor to understanding experience is effective engagement (i.e., partnership). Patient and caregiver engagement activities can range from providing input into care plans, to co-designing services, and setting organizational priorities (Carman et al., 2013). A recent systematic review demonstrated that engaging people in their care (at these various levels) can enhance care experiences and outcomes (Bombard et al., 2018).

While there is a critical role for patient and caregiver engagement at the leadership and governance level, this practice brief focuses on patient and caregiver experiences and engagement at the micro level—the care interactions that people and their caregivers have with front-line staff and care teams. Not only do we look at what an optimal experience entails, but outline how providers engage patients and caregivers in care to optimize their experiences.

We focus on people with complex care needs as well as family and friend caregivers. People with complex care needs tend to have multiple health and social care needs and are poorly understood despite using health care more than the general population (Wodchis et al., 2016). Importantly, some people with complex care needs are not connected to the health care system and are at risk

of decline and poor outcomes. Caregivers (typically unpaid family members and friends) shoulder a huge burden, often making enormous sacrifices as they provide care (in their personal and work lives). Caregiving is often met with financial challenges (stemming from lost days at work and through the cost of equipment, medication, home modifications and services not covered through Medicare or other insurance schemes. Caregivers report feeling unrecognized, excluded from the care team, and have few breaks even when services are in place (Kuluski et al., 2018).

#### How this relates to Ontario Health Teams

This practice guide will provide Ontario Health Teams (OHTs) with practical guidance on how to 1) address the things to matter most to patients and caregivers and 2) engage with patients and caregivers to enhance their relationships with them and improve their care. Through practical activities at the end of this document, OHTs can review their own strategies to engage patients and families (and that of their partner organizations) and outline barriers and facilitators to effective patient and caregiver engagement.

This practice guide provides concrete examples of what matters most to patients and caregivers in their care along with specific details of how things look when they work well. While some of these things may be known (or implemented) by your care team, some examples may offer new ideas on how to enhance people's experiences in your practice.

#### INSIGHTS

#### How we uncovered what matters to patients and caregivers

We draw our examples from a multi-jurisdiction study including 173 ethnically diverse older patients with complex care needs and their caregivers (mostly family), from Ontario, Quebec and New Zealand. These patients and caregivers participated in one-to-one in-person interviews to share their experiences and care needs. Patients and caregivers were using an array of services including primary care, home and community care, specialist care, hospital, emergency rooms and rehabilitation services. Many patients and caregivers relied on community and social services to manage transportation, food, housing and social activities in addition to health services.

Following in-depth analyses of interview content, the things that mattered most to patients and caregivers across these multiple jurisdictions of study were synthesized and described. We learned not only what mattered most to patients and caregivers but about the activities that supported these things. We also looked at the things that get in the way of people engaging (i.e., participating). It is critical to understand barriers to engaging patients and caregivers to ensure that steps are taken to create a comfortable environment for patients and caregivers, from all generations, cultures and linguistic groups, to participate in a way that is meaningful to them.

We understand that your target populations will include other groups, aside from older adults with complex care needs, including children with medically complex care needs, people with developmental disabilities, episodic acute care needs, etc. While we suspect that core attributes of care will be similar as to what is detailed below, as an OHT it will be important to determine other things that matter to patients and caregivers, which can be determined through the strategies and examples provided below.

#### What matters most to patients and caregivers in their care

Patients and caregivers want to be heard; have someone they can count on; know how to manage health and what to expect; easily access health and social care; be independent; and feel safe.

### What matters most to patients and caregivers is that they...

- 1/ Be heard
- 2/ Have someone they can count on
- 3/ Know how to manage health and what to expect
- 4/ Easily access health and social care
- 5/ Be independent
- 6/ Feel safe

- 1/ Being heard captures the relational aspects of care and is characterized by many activities including:
  - Treating patients and caregivers like equal partners (having a friendly demeanor, using a neutral tone of voice, creating a comfortable space to interact)
  - > Not rushing them
  - > Asking about non-health care related things (social activities, family members, etc.)
  - > Listening intently
  - Understanding (and asking about) their preferences and incorporating this knowledge into care planning

Patients and caregivers are more likely to feel heard, appreciated and comfortable if their provider(s) and care team is consistent over time. Having consistent care providers will enhance familiarity and foster trust. Empathy is also an important trait that is required of all parties in the care interaction (patient, caregiver and provider). While it's not possible to completely relate to another person's experience until you have walked in their shoes, exercising empathy (trying to understand and acknowledge the feelings of another) can enhance the relationship and support the management of expectations.

For example, in getting to know a patient, you may come to understand that self-care is difficult given the stresses felt in other parts of their life. In response, recommended self-care strategies can be adapted to suit the unique needs of the patient, and if applicable, their families or care partners. Likewise, when a patient recognizes your constraints (as a provider), they may adjust their expectations, so long as they feel that you care about them and are doing what's possible to meet their needs.

- 2/ Having someone to count on helps patients and caregivers get access to the broader system. This "counted on" person is typically a paid provider who serves a coordinating function and has access to a broader interdisciplinary team with whom they regularly interact and can contact with questions. The trusted go-to person is:
  - > Easily accessible to the patient or caregiver by text, phone or email
  - Can get resources/questions answered from other team members in a reasonable amount of time (and manages expectations around response times)
  - Keeps track of appointments, sends reminders and determines if the patient is able to get there

This 'go-to person' connects patients to needed community based resources including primary care to avoid unnecessary hospital and emergency room visits. This role can also alleviate caregiver stress, by getting timely responses to care related questions and concerns.

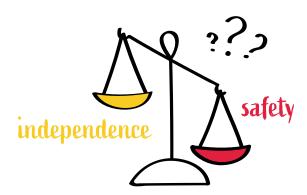
- 3/ Knowing how to manage health and what to expect. Patients and caregivers want clear information on their health status and know what they might expect in the future regarding their care, symptoms and needs (even if things are uncertain). Key supporting activities include:
  - Using lay language (avoiding the use of complex medical jargon)
  - Teaching patients and caregiver's skills to self-manage by providing a written list of steps, or 'how-to' guides, exercises, etc. that take into consideration their contexts and capabilities
  - Accepting (and preparing patients and caregivers for) a 'trial and error' approach

- to health management (trying different treatment/medication regimens, and working closely with them by checking in continuously and modifying the plan as needed)
- > Providing clear explanations as to why certain treatment options are being recommended and what to expect
- Working with caregivers to anticipate and prepare for a patient's future trajectory (e.g., stages of dementia and decline)

Managing expectations through dialogue such as, "we might not get it right the first time, but let's try this first and I'll follow-up with you" helps patients and caregivers understand that complex care management requires 'continuous tweaking' as opposed to a silver bullet solution.

- 4/ Easily accessing health and social care that is meaningful is activated through the 'go-person' described earlier. Access to health care resources (doctor's and specialist visits, homecare) as well as social care resources (such as getting to the grocery store with ease, participating in social activities and hobbies) is typically required. At times, access is only met 'half way' for example, a specialist appointment may be booked but transportation is not arranged or an assistive device is delivered to the patients home but not installed. Example activities in support of access include:
  - Offering different methods of service provision to accommodate patient function (home visits, videoconferencing, etc.)
  - Allowing patients and caregivers to easily change appointments if not feeling well
  - Providing health and social care services under one roof or within a similar neighborhood

- Coordinating medical appointments <u>and</u> transportation
- > Spanning boundaries (having food available at the primary care clinic or organizing a community group to offer programs in spaces where patients get medical care)
- Ensuring that resources offered can be fully utilized (e.g., knowing all the steps required to get someone to their appointment)
- **5/ Being independent** is a top priority for patients and something that caregivers try to honour as much as possible, even as patients decline physically or cognitively. Being independent is supported by:
  - Assistive devices inside and outside the home to support easy navigation and mobility
  - Opportunities for patients and caregivers to participate in enjoyed activities (traveling, hobbies, visits with friends)
  - Caregivers getting a "true" break (e.g., respite) by having a trusted and familiar provider available that the patient feels comfortable with so the caregiver can get away and not worry about the patient
  - Giving patients and caregivers choices in their care plan

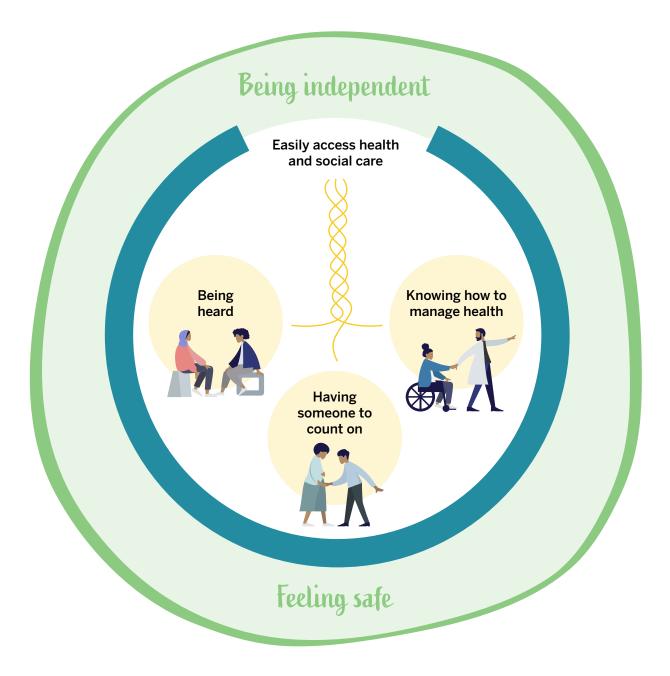


Being independent is intricately connected to (and sometimes trades off with) <u>safety</u>. As noted above, caregivers try hard to preserve patient independence for as long as possible but at certain points (typically as patients approach the latter stages of functional decline or onset of dementia) they become more concerned about safety. Caregivers, at times, feel distressed as they try to determine the right balance <u>between</u> independence and safety. Patients continue to prioritize independence and do not always understand why activities are restricted.

- **6/ Feeling safe** (minimizing risk) both inside and outside the home is important to patients and caregivers. Activities that support feeling safe include:
  - Training patients and caregivers on how to use mobility aids inside and outside the home
  - > Ensuring that caregivers can safely perform transfers and personal care without putting their health at risk (may require training, equipment or help from an extra person)
  - > Getting someone to go to the patient's home and working with caregivers to address care needs (such as behaviours and unpredictable events that typically arise with dementia or complex medical treatment)
  - > Providing caregivers with additional supports to offer peace of mind so they are able to attend appointments or social outings and know the patient is safe

The things that matter to patients and caregivers overlap, intersect and sometimes trade-off (see Figure 1).

Figure 1/ The intersection of the things that matter most to patients and caregivers.



**Figure description:** Being heard, having someone to count on, and knowing how to manage health can be thought of as three key attributes of a care delivery model when patients and caregivers access health and social care (three inner circles linking to the fourth at top).

While health care includes medical and professional supports (in a clinic or home setting such as nursing, occupational therapy and physician care), social care includes both instrumental activities of daily living (supports with housecleaning, meals,

medication management) as well as the social determinants of health (housing, financial support, food security, etc.).

Core attributes such as independence and safety (outer circle) can be thought of as outcomes (patients and caregivers feeling as safe and independent as possible). Finding the appropriate balance between independence and safety is key and will require priority-setting between patients, families and care teams.

#### Factors that influence patient and caregiver engagement in their care

In addition to understanding what matters most to patients and caregivers, there are a number of factors that <u>influence</u> patient and caregiver <u>engagement</u> in care. These include their perception of services; their comfort in asking for things; their beliefs about roles; and their access to resources.

## Patient and caregiver engagement is influenced by their...

- 1/ Perception of services
- 2/ Comfort in asking for things
- 3/ Beliefs about roles
- 4/ Access to resources

More specifically, patients and caregivers are reluctant to use what is available or offered to them if they perceive the quality of care to be poor. These perceptions of poor quality are shaped by previous experiences or their observations of others experiences.

Patients and caregivers are reluctant to ask for things if they feel the 'system' is not able to respond to them or if they fear being reprimanded for voicing unmet need.

Role beliefs such as perception of whether or not it is appropriate to question care providers or relinquish personal responsibilities (such as caregiving duties) also plays a role. For example, cultural or generational factors may influence a patient's willingness to question their care team or engage in goal setting activities.

Finally, factors such as a common language, adequate health literacy and access to financial resources influence the extent to which patients and caregivers can meaningfully participate in their care.

These factors that influence engagement relate to the core attributes of care. For example, patients and caregivers are more likely to feel comfortable asking for things if they are working with a provider (or team) that they know and trust. Furthermore, the 'go-to' person is often the person who connects patients and families with tools (financial resources, translators, information, and selfmanagement resources) to enhance engagement.

#### Three key takeaways

The things that matter most to patients and caregivers include relationships (how they feel when they interact with providers) as well as activities that make them feel human (hobbies) not just having medical needs addressed.



Taking the time to get to know patients and their caregivers will not only help them feel heard, it will help providers and teams understand the things that get in the way of them managing their health and participating in their care.



Activities to support self-management of care needs to consider the context of the patient and family (where they live, their comfort in their surrounding community and accessibility to health and social activities) as well as their ability to access resources (finances, etc.) to supplement care.

#### EXERCISE: SELF-ASSESSMENT

We now ask you to reflect on the types of resources and tools that your practice has regarding patient and caregiver engagement (with a focus on addressing barriers to engagement).

Does	Does your practice nave	
D	A point person that patients and caregivers feel comfortable contacting with questions or making complaints?	
D	Translation services/interpreters available for patients and caregivers who don't speak the same language as their providers?	
D	Self-management/educational resources available in the preferred language of patients/caregivers?	
D	A point person to assess additional resources required (such as financial support, volunteer services) that might be required for patients and caregivers to manage care?	
D	An understanding of the preferences/expectations/capabilities of the patients and caregivers regarding their role (e.g., is the family comfortable having strangers coming into the home to provide personal care)	
D	Opportunities for patients and caregivers to participate in various modes of engagement (such as co-design of care services or sitting on organizational planning committees?)	
D	Resources and supports to orient staff and managers to the philosophy of patient engagement (e.g., training for staff)?	

As an OHT, we recommend that you connect with your partner organizations to see what kinds of strategies they have in place to engage patients and caregivers. What works and what needs to change from their point of view? Taking note of this will help you leverage the strengths of your partners and build a common approach together. We recommend building in an in-person, brainstorm session to share strategies.

#### SCENARIOS

We now share two scenarios to illustrate a real-world example of what it looks like when the needs and preferences of the patient and caregiver are understood and addressed versus not.



#### Poor outcomes

Needs and preferences of patient and caregiver are NOT understood or addressed.

#### One day...

Mrs. Lee woke up feeling unwell. She's an 87-year-old widow and lives alone in her apartment. Her daughter, Laura, just returned from a short vacation and tries to reach her Mom by phone, and after several tries there is no response. She drives over to check on her. When she arrives, her Mom appears confused and tells her daughter that she feels dizzy.

There have been several coordinators involved in her Mom's care and she is unsure who to contact. She doesn't feel comfortable calling the primary care doctor directly so she calls 911 and her Mom is taken to the emergency room where she waits for several hours. Laura and her mother meet with several people where they have to repeat their story over and over again.

They decide to keep her overnight to run tests. Due to a lack of rooms she is in a stretcher in a hallway where it's noisy and unfamiliar. Laura is exhausted and frustrated at the lack of timely response to her Mom's needs. Her Mom is scared and eats very little, making her feel increasingly tired and weak. She misses another dose of her medication as she waits and is feeling increasingly dizzy.

On her way to the washroom she has a fall and fractures her hip and is now waiting for surgery. Given the lack of operating rooms she waits for several days and then catches pneumonia which further delays her surgery. Laura, the sole family caregiver is exhausted, confused, frustrated and takes several days off work without pay so she can be there to advocate for her Mom who doesn't speak English.

#### SCENARIOS

We now share two scenarios to illustrate a real-world example of what it looks like when the needs and preferences of the patient and caregiver are understood and addressed versus not.



#### Good outcomes

Needs and preferences of patient and caregiver are understood and addressed.

#### One day...

Mrs. Lee woke up feeling unwell. She's an 87-year-old widow and lives alone in her apartment. Her daughter, Laura, just returned from a short vacation and tries to reach her Mom by phone, and after several tries there is no response. She drives over to check on her. When she arrives, her Mom appears confused and tells her daughter that she feels dizzy.

Their care coordinator, Sandra, whom Mrs. Lee and Laura have gotten to know quite well over the years, always encourages them to call if they need something. Mrs. Lee doesn't feel comfortable asking for help, but her daughter knows to contact Sandra when something is wrong. She rings Sandra and she answers quickly and listens to Laura's concerns. During this phone call her Mom starts to feel better but is very tired.

Sandra is in regular contact with Mrs. Lee's primary care team and is able to arrange a home visit with her primary care provider that afternoon. During the home visit Mrs. Lee has her vitals checked and blood work done and later it's determined that she needs to adjust her medication. The primary care doctor calls the pharmacy and arranges for the new medication to be dropped off.

During this visit it's also clear that Laura is feeling burnt out and is concerned about leaving her Mom alone for long periods of time during the day while she is at work. The primary care doctor shares this with Sandra who connects back with Laura to tell her about a Day Program that caters to the Chinese population. Since the day program is with her Chinese speaking peers, Mrs. Lee agrees to go, and her daughter, who gets to know the staff, feels comfortable knowing that her Mom is happy and safe. Attending the program also helps Mrs. Lee feel independent as she does not want to move into a long-term care facility.

#### SCENARIO QUESTIONS

If faced with the scenario (in bold, above), what tools and approaches would your team use to respond to Mrs. Lee and Laura (her caregiver)?

- 1/ For example, would Mrs. Lee and her caregiver know who to call on your team?
- 2/ Who would be responsible for responding to the needs of Mrs. Lee and her caregiver?
- 3/ What types of tools or approaches would your team use to address the needs of Mrs. Lee and her caregiver?
- **4/** What barriers would you anticipate in meeting the needs of Mrs. Lee and her caregiver?
- 5/ How would you/your team continue to engage with Mrs. Lee and her caregiver if you wanted to draw on their experience to design improvements in your practice?
- 6/ Regarding Mrs. Lee and her caregiver, what engagement barriers do you anticipate and how would you address them? (hint: Laura, the caregiver, has a very busy work schedule and Mrs. Lee does not speak English)

#### REFERENCES

- 1/ Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, and Sweeney J. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff (Millwood). 2013; 32(2):223-31.
- 2/ Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S, Onate K, Denis JL, and Pomey MP. Engaging patients to improve quality of care: a systematic review. Implement Sci. 2018; 13(1):98.
- 3/ Wodchis WP, Austin PC, and Henry DA. A 3-year study of high-cost users of health care. CMAJ. 2016; 188(3):182-188.
- **4/** Kuluski K, Peckham A, Gill A, Arneja J, Morton-Chang F, Parsons J, Wong-Cornall C, McKillop A, Upshur REG, and Sheridan N. "You've got to look after yourself, to be able to look after them" a qualitative study of the unmet needs of caregivers of community based primary health care patients. BMC Geriatr. 2018; 18(1):275.



#### 3 practice guide summary

#### How can patient and caregiver needs be met by providers and managers?

In this practice guide, we present the activities done by providers and managers working in integrated care models and discuss how these meet patient and caregiver needs.

## What activities are done by providers and managers in integrated care?

We present 32 activities done by providers and managers working in integrated models of care. We distinguish the activities as occurring on either the <u>front-stage</u> or <u>back-stage</u> of care delivery:

- 1/ Provider front-stage activities involve interactions between providers and patients
- 2/ Provider back-stage activities involve interactions between providers
- 3/ Manager front-stage activities involve interactions with staff and patients
- 4/ Manager back-stage activities involve interactions with other managers and stakeholders

We illustrate how these activities are interrelated, with the success of some relying on the presence of others. Importantly, we show how providers and managers will require diverse skill sets (including both technical and relational skills) in order to engage in both front-stage and back-stage activities.

The presented interconnected activities can be used as a starting point for Ontario Health Teams, but these should be co-designed to fit local contexts and regularly monitored through the implementation process to ensure they are helping meet patient and caregiver needs.

#### What are the 3 key takeaways?

1

Identify what activities you are already doing across partners at both the front-stage and backstage and see where there are gaps. Think about how activities are interconnected and co-dependent. Components already in place may require adaptation and modification to align with an integrated model with network partners.



When building teams of providers and managers, think about the diverse skill sets needed to be able to engage in both front-stage and back-stage activities. Often both clinical and relational skills will be required to be successful in both front-stage and back-stage roles.



The 32 activities of providers and managers can, and should, be adapted to local contexts through co-designing with providers, patients and families.

**AUTHORS** 

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## How can patient and caregiver needs be met by

# PROVIDERS & MANAGERS?

### INTRODUCTION

### Why this is important

Once committed to the vision of delivering more integrated health and social care services to meet the needs of patients and families, the next step is determine what front-line staff and management teams will actually do make it a reality.

A recent scoping review found that models of integrated care include a number of key components including: person-centredness, holistic or needs assessment, integration and coordination of services, collaboration, and selfmanagement (Struckman et al., 2018). These components can be achieved through different activities that providers and managers engage in every day as part of the delivery of care. However, research in the field of integrated care has demonstrated that it is not simply about putting a new set of processes in place, but about understanding how these processes interact with one another and work within different contexts to achieve desired outcomes (Shaw et al., 2018: Kirst et al., 2017; Vargas et al., 2015).

This guide uncovers the activities of front-line providers and managers working in integrated care models; discussing what these activities look like, how they're different from how you may have been working before, and, perhaps most importantly, how these activities are linked and related to each other. For the purposes of this guide, the term providers refers to clinical and point-of-care staff (physicians, nurses, social workers, therapists, care coordinators, physician assistants, volunteers, and reception/clerical staff) that interface directly with patients and caregivers to deliver health and social care services. The term managers refers to administrative staff that support, guide and lead operational processes (administrators, IT support, quality improvement staff, managers, directors). The two Mrs. Lee case vignettes are used to illustrate how front-stage and back-stage activities can lead to each of these two scenarios.

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### **How this relates to Ontario Health Teams**

Ontario Health Teams (OHTs) will be tasked with providing a "full and comprehensive continuum of care at maturity" (MOHLTC, 2019). This will require redesigning care pathways that encompass a full continuum of care within and across organizational partners, with an aim to establishing care teams that will be responsible for delivering services across that continuum.

OHTs can use this practice guide to identify activities that care teams and managers engage in when delivering integrated care. Importantly, this document will help OHTs to: 1) identify the more obvious front-facing activities of care delivery they will need to engage in (e.g., setting up a care plan), as well as the less obvious; and 2) link front-facing activities to less obvious back-end processes and managerial support activities (e.g., building a supportive and collaborative culture) required for those care teams to be successful.

### INSIGHTS

## Meeting patient and caregiver needs through provider and managerial activities: Lessons from the literature and iCOACH study

The accompanying patient and caregiver practice guide summarized 6 attributes of the care experience that matter most to patients and caregivers. Taking these attributes as a starting point (representing the desired outcomes of patients and their families), we link practical activities of providers and managers that support these attributes. To identify these activities, we engaged in: 1) a targeted literature review identifying existing reviews of key activities of integrated care; 2) a symposium session with managers and providers who deliver integrated care services to review and discuss the value of these activities; and 3) comparing the findings of the literature review to data from the iCOACH study. This strategy yielded a list of 32 activities of providers and managers delivering integrated care for older adult patients.

Notably, these activities overlap with the critical success factors identified in the accompanying practice guide on implementation, demonstrating that some of the factors can and should be achieved through the activities of both managers and providers. This connection between success factors and the provider and manager activities of care delivery further demonstrates the importance of collaborative leadership approaches as successful implementation is contingent on the work of leaders driving the change, as well as the activities of providers and managers engaging in the change.

The list of 32 activities emphasizes the day-to-day work and processes that providers and managers will need to engage in to support an integrated model of care. Some of these activities are more obvious and explicit in the delivery of integrated care and play a front-facing role; for instance, intaking new patients or creating a care plan with an inter-professional team. However, what the iCOACH study (Shaw et al., 2018) and other research on integrated models has shown is that these activities can only be successful if other processes or activities are in place in the back-end (Kirst et al., 2017; Vargas et al., 2015; Ling et al., 2012). For example, creating environments that support strong relationship building between providers is critical to help support professionals to work effectively as a team (Karam et al., 2018).

### Front-stage and back-stage activities

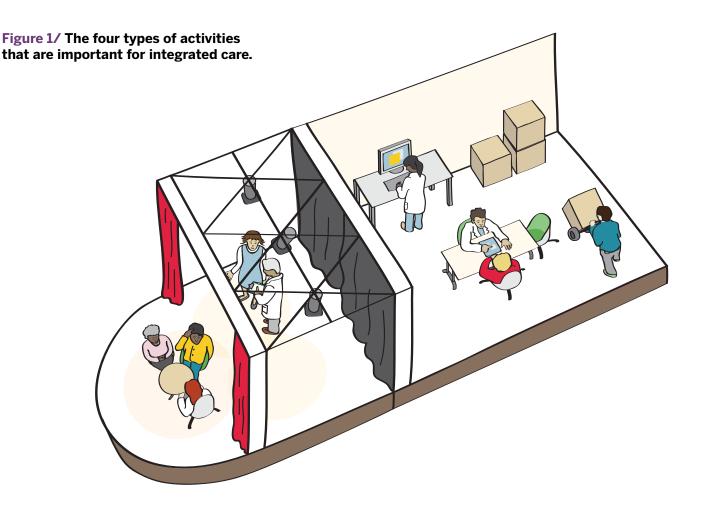
To unpack these multiple-layers and interrelationships, we use the analogy of front-stage and back-stage to describe the types of activities required of providers and managers to realize integrated care. This is not to suggest that one layer of activity is more important than another, but rather to bring to light how the layers interact, and require that providers and managers play multiple, and sometimes new, roles to engage in these different types of activities. Understanding these roles more clearly can help in assigning tasks best suited to the training and skills of providers and teams, and can further help identify competency gaps amongst teams to help drive training and hiring planning (see Figure 1).

The front and back-stage activities presented in the next section may represent entirely new work by providers and managers or an expansion and re-design of activities already in place. Adaptive change approaches outlined in the implementation practice guide may be particularly useful in redesign work as it will involve modification of the

existing work flows rather than necessarily putting in entirely new activities and processes. Activities may require expanded roles for providers and managers who will need to engage in new ways of thinking about work (new cognitive models) as part of the shift towards more integrated models of care (Nutting et al., 2011).

Table 1 maps the 32 activities of integrated care models to the attributes of patient and caregiver experience and organizes them into front-stage and back-stage work of providers and managers. In reviewing the table, it should be noted that: 1) provider and manager activities are mapped to the first 4 attributes that are specifically related to care processes. These activities are expected to result in achieving the last 2 outcome-oriented attributes (independence and safety); and 2) providers and managers sometime share activities in the front-or back-stage. These shared roles of front-line providers and leaders point to the importance of engaging in bottom-up change discussed in the implementation practice guide.

Finally, we note some activities as "foundational," meaning they do not align to specific attributes of patient and caregiver experience, but rather act as important enablers to the other activities listed above. As such, these activities mainly occur at the back-stage.



## Front-stage and back-stage activities can be defined as...

### 1/ Provider front-stage

Activities that are patient- or caregiver-facing. These are any activities involving interactions between providers and patients or their caregivers, whether synchronous or asynchronous (e.g., clinic visits, phone calls, video conferencing, emails).

### 2/ Provider back-stage

Activities that are provider- or manager-facing. These are any activities involving interactions with other health or social care providers (internal or external to their organization), volunteers or managers, or independent administrative and preparatory work (e.g., charting, case conferencing, training and education) without direct contact with patients or caregivers.

### 3/ Manager front-stage

Activities that are patient-, caregiver- or providerfacing. These are any activities involving interactions with patients, caregivers, or health or social care providers (internal or external to their organization), volunteers or managers.

### 4/ Manager back-stage

Activities that are manager- or stakeholder-facing. These are any activities involving interactions with other managers (internal or external), care delivery stakeholders (from collaborating organizations), policy stakeholders (health ministries and regionally-based organizations with a mandate to drive care delivery or quality), other funders (e.g., charitable, not-for-profit and philanthropic funders), or independent administrative and preparatory work stakeholders (e.g., preparing staff meetings, problem resolution, change management, any co-design work).

## Table 1/ The 32 activities of integrated care mapped to attributes of patient and caregiver experience.

### Foundational activities

These activities are at the provider and managerial level and cross cut the attributes by enabling other activities

### For both providers and managers

- > Supporting experimentation in design and delivery of collaborative, patient-centered care
- > Supporting adoption and meaningful use of IT systems
- > Engaging in regular performance measurement and quality improvement activities and initiatives

### Provider back-stage

> Developing approaches to manage the cost of delivering integrated care services

### Manager front-stage

> Supporting clinician involvement in service planning, and implementation of new initiatives

### Manager back-stage

- > Creating forums and opportunities for learning from external experts and organizations
- > Ensuring providers and case managers have appropriate and feasible caseloads
- > Ensuring that organizational mandates and strategic directions continually promote integrated care as a core mission
- > Developing approaches to manage the cost of delivering integrated care services

#### Attribute 1

### Being heard

### Examples

- Provider focuses on the person outside the diagnosis
- Provider probes for personal context outside of health care to understand family/ social life, interests, and priorities for patients and caregivers
- Patients and providers talk to each other, sharing appropriate information so everyone knows what is going on.

### **Provider front-stage**

- 1/ Giving patients and caregivers opportunities to share what is most important to them in their care and including these preferences in individual care planning and decision making
- 2/ Addressing broader determinants of health that impact patient and caregiver's experiences

### Provider back-stage

- 3/ Exchanging information (such as patient records or notes) with providers within your organization and across health and social care continuum.
- **4/** Using technologies to improve information exchange, service delivery, access to data, and communication for client care
- 5/ Ensuring specific patient data is routinely collected in health records so that all team members have the same information
- **6/** Building effective professional and interpersonal relationships with providers and other members of each individual patient's healthcare team
- 7/ Engaging in inter-professional teamwork (with health care providers from other disciplines), within your organization and outside of your organization (e.g., creating shared-care plans)

### Manager front-stage

- **8/** Using technologies to improve information exchange, service delivery, access to data, and communication for client care
- **9/** Ensuring patients and service providers from different sectors can access and share information electronically (e.g. patient records/charts.)
- **10/** Ensuring shared understanding among the healthcare team regarding roles, responsibility, accountability, and communication
- 11/ Building effective professional and interpersonal relationships with providers and other members of each individual patient's healthcare team

### Manager back-stage

- **12/** Addressing broader determinants of health that impact patient and caregiver's experiences
- **13/** Ensuring specific patient data is routinely collected in health records so that all team members have the same information

### Attribute 2

## Having someone to count on

### Examples

Having a trusted 'go-to'person (typically a paid provider) who is:

- Responsive and can connect to the broader team when needs arise
- Accessible so the patient/caregiver have direct contact details and able to reach them directly
- Easily identifiable for patient/caregiver

### **Provider front-stage**

**14/** Routinely monitoring patients' status (e.g. strategically scheduled follow-up assessments)

**15/** Ensuring that patients and caregivers have someone they can contact if health and social care needs arise

### **Provider back-stage**

**16/** Ensuring case managers have appropriate skills and expertise to execute their roles

### Manager front-stage

17/ Ensuring that patients and caregivers have someone they can contact if health and social care needs arise

### Manager back-stage

**18/** Ensuring case managers have appropriate skills and expertise to execute their roles

### Attribute 3

# Knowing how to manage health and what to expect

### Examples

- Instill confidence in patient and family by teaching them skills to self-manage
- Providing instructions, written list of steps, how-to guides on how to manage symptoms, and activities (e.g. specific exercises to support better function)

### **Provider front-stage**

19/ Promoting and supporting selfmanagement practices

**20/** Linking patients, families and/or caregivers to informational/educational and community resources

### Manager front-stage

- 21/ Involving patients and caregivers in service (co)-design and organizational decision-making processes
- **22/** Linking patients, families and/or caregivers to informational/educational and community resources
- 23/ Promoting and supporting selfmanagement practices

### Attribute 4

## Easily accessing health and social care

### Examples

Access enabled by having a 'go-to' person who:

- Works to connect and facilitate access to health and social resources
- Wears multiple hats so both health and social needs can be met simultaneously (e.g., physician who teaches tai chi, social worker that can provide transportation tokens or liaise with housing support)
- Mobilizes services and resources

### **Provider front-stage**

24/ Identifying a single point of access for onboarding and assessing new patients

**25/** Facilitating transitions across care settings for patients and caregivers

### Provider back-stage

**26/** Following clear and consistent criteria to identify patients who will benefit from integrated community-based health and social care services

27/ Ensuring effective flow and tracking of patient referrals (i.e. referrals are accepted, sent and followed up on, within your organization and across other organizations in the health and social care continuum)

### Manager front-stage

[26/] Following clear and consistent criteria to identify patients who will benefit from integrated community-based health and social care services

[27/] Ensuring effective flow and tracking of patient referrals (i.e. referrals are accepted, sent and followed up on, within your organization and across other organizations in the health and social care continuum)

**28/** Facilitating transitions across care settings for patients and caregivers

### Manager back-stage

29/ Identifying a single point of access for onboarding and assessing new patients

**30**/ Building collaborations with organizations within the local healthcare geography to promote improvements to patient care

**31/** Developing formalized agreements between organizations (e.g., data sharing or co-location agreements)

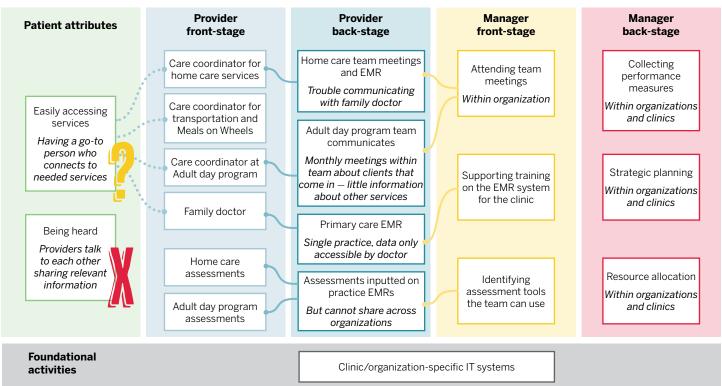
**32/** Assessing patient and population needs to inform the planning of services

### SCENARIOS

To demonstrate how these activities may change what is already being done on a day-to-day basis, we present activity maps around the two scenarios of Mrs. Lee presented in the patient and caregiver practice guide (also included in the appendix for this guide). In these scenarios, we see two very different stories unfold after Mrs. Lee, an 87-year-old widow, wakes up feeling unwell one day. Figure A below illustrates what activities are in place when her needs are not understood nor addressed. Figure B depicts the activities in place when her needs are met.



Provider and manager activities when needs and preferences of Mrs. Lee and her daughter are NOT understood and addressed and the process of care is broken.



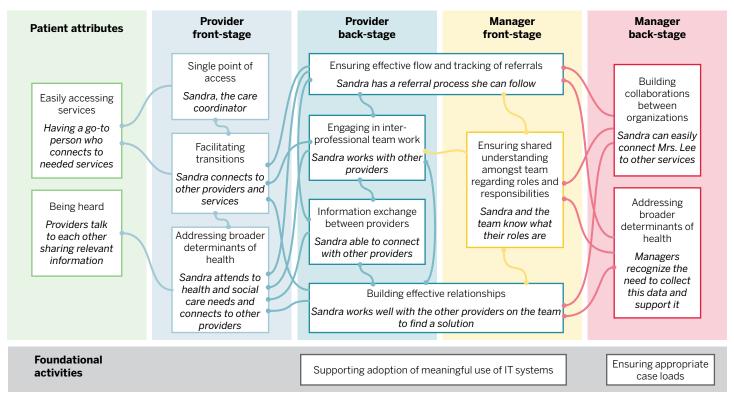
### **Discussion of Scenario A**

The model of care offered to Mrs. Lee has many components that have likely helped her in her care to this point. She has access to a primary care doctor and care coordinators that have been providing her with care plans and health and social care services to help her stay independent at home. The breakdown in this scenario happens early on. While Mrs. Lee seems to have a lot of support, a clear single point of contact with a person that Mrs. Lee and her daughter trusts to deal with this situation has not been established.

All the supporting structures at the back-stage and managerial level are similarly fragmented, offering support only to their single teams or organizations rather than creating meaningful connections across the team. The components are in place, but there is no communication between the players, leaving Mrs. Lee and her daughter uncertain of what to do, who to go to for help, and thus ending up in the ER with unnecessary secondary negative outcomes.



Provider and manager activities when needs and preferences of Mrs. Lee and her daughter are understood and addressed and the process of care is integrated.



### **Discussion of Scenario B**

In this second scenario Mrs. Lee has many of the same services available as in the first scenario, the key difference being that she and her daughter know to call Sandra who has established good relationships with her other providers and a strong communication pathway. Sandra additionally addresses broader determinants of health for both Mrs. Lee and her daughter, attending to caregiver burnout in a proactive way. As can be seen in Figure B, Sandra's ability to work with Mrs. Lee and her daughter and connect them to the health and social services required is reliant on a number of back-stage activities, notably:

 Providers afforded the ability to exchange information with other providers within

- and across organizations, enabled through available technologies
- > Providers engaging in inter-professional teamwork within and across organizations
- Managers supporting the building of effective professional and interpersonal relationships between providers in the circle of care
- > Managers ensuring a shared understanding of the team regarding roles, responsibilities, accountability and communication
- Managers building effective professional and interpersonal relationships and partnerships across organizations

While Sandra, the care coordinator, is doing much of the front-stage work in this scenario, she may also need to hand-off care to someone on his team. For instance, where Sandra was able to call other providers to get advice regarding Mrs. Lee's medication in this scenario, many models could also facilitate home visiting by multiple team members, such as a physician's assistant, pharmacist, or family physician, who could come in to Mrs. Lee's home to assess her needs in collaboration with Sandra, Mrs. Lee and Mrs. Lee's daughter to determine the best course of action.

Establishing flexible staffing and funding models that can adapt to changing needs of patients can support this type of team work. Alternately using technologies like video conferencing, and secure messaging, can help the team to easily connect and trouble shoot. Keeping in mind potential restrictions on professional roles will also be important in determining the best individuals to be involved in these more flexible positions. For instance, unionized professions may experience more barriers to adaptation and variation in work processes.

The relationship between these activities cannot be understated and demonstrates that providers and managers will require diverse skills sets to engage in both front-stage and back-stage activities. In this mapping we can see that providers need clinical skills to engage with patients and families, as well as strong collaborative and teamwork skills to work with other professionals. Managers also not only require skills in directing staff, but they also need good relational skills, as well as an ability to build a collaborative culture within and across organizations.

### Co-designing a front-stage back-stage map

The activities list linked to front and back stage activities offered in Table 1 can act as a starting point to identify what activities will help meet patient/client values and outcomes. It should be noted some of these activities are identified in generalized ways (e.g., ensuring that patients and caregivers have someone they can contact if health and social needs arise). We purposely do not specify who this person needs to be on the team as we have found these details are best left to be determined by the teams who need to adapt these activities to their own contexts.

For example, one model may rely on a single care coordinator who would act as the central point of contact for all patients on their roster, whereas another model may deploy an inter-professional team and the main point of contact may be the individual with whom the patient/client is most comfortable. Both examples work well in different contexts. In order to determine the best way to operationalize these activities we suggest working together with the providers and managers delivering the services to establish processes (Ham and Walsh, 2013), and, where possible with patients and families as well (Rocco, 2016). We further recommend revisiting these processes regularly to adapt, modify and refine, particularly in the early phases of implementation outlined in the implementation practice guide.

### How to know if you are doing this well

The advantage of mapping front and back-stage activities of providers and managers is that it can help identify where there may be gaps in processes that are impeding progress towards programs goals. As can be seen in the difference between Figures A and B, the linked activities

show where different providers and managers need to act in the process of delivering care. If evaluations are demonstrating that the program is falling behind addressing any of the 6 attributes of patient and caregiver experience, go back to the activities map to see where the problems may be. It is recommended this activity is done with all providers and managers involved in the activity chain so different perspectives can be represented.

The mapping of activities also offers an opportunity to engage in co-designing solutions with providers and managers (as well as patients and families), which can improve team engagement. When an issue arises look to the maps created together. The scale ratings done at the beginning of this section can also be revisited to check-in on these core components of delivering an integrated model of care. Discuss as a team how to move the dial.



### Three key takeaways

Identify what activities you are already doing across partners at both the front-stage and back-stage and see where there are gaps. Think about how activities are interconnected and co-dependent. Components already in place may require adaptation and modification to align with an integrated model with network partners.



When building teams of providers and managers, think about the <u>diverse</u> <u>skill sets needed</u> to be able to engage in both front-stage and back-stage activities. Often both clinical and relational skills will be required to be successful in both front-stage and back-stage roles.



The 32 activities of providers and managers can, and should, be adapted to local contexts through codesigning with providers, patients and families.

### EXERCISE: MAP YOUR ACTIVITIES

Now that you have learned about front-stage and back-stage activities for integrated care, use the steps below to map out the activities needed to achieve one of the 6 patient and caregiver attributes within your OHT. Remember, integrated care is a team sport – do this exercise with your team.

To ma	p your activities
D	Pick one attribute from the 6 that matter most to patients and families that you'd like your OHT to tackle.
D	Map out the front-stage and back-stage activities of all partners in your OHT to achieve the attribute, including both provider and manager levels. Some of these activities may already be in place and some may be new. Use the 32 integrated care activities to help you.
D	Next draw links between the activities, and try to identify who on the team will engage in these activities. The links will help you visualize how you need to structure teams and communication processes to enable your activities in your OHT.
D	Finally identify what can help you realize this vision and what might be standing in your way. Think about how you can mitigate these barriers.

### REFERENCES

- 1/ Struckman V, Leitjen FRM, van Ginneken E, Kraus M, Reiss M, Spranger A, Boland MRS, Cyzpionka T, Busse R, Rutten-van Molken M, SELFIE consortium. Relevant models and elements of integrated care for multi-morbidity: Results of a scoping review. Health Policy. 2018 Jan;122(1):23-35. doi: 10.1016/j.
- **2/** Shaw J, Steele Gray C, Baker GR, Denis JL, Breton M, Gutberg J, Embuldeniya G, Carswell P, Dunham A, McKillop A, Kenealy T, Sheridan N, Wodchis WP. Mechanisms, contexts and points of contention: operationalizing realist-informed research for complex health interventions. BMC Med Res Methodol. 2018 Dec 27;18(1):178. doi: 10.1186/s12874-018-0641-4.
- **3/** Kirst M, Im J, Burns T, Baker GR, Goldhar J, O'Campo P, Wojtak A, Wodchips WP. What works in implementation of integrated care programs for older adults with complex needs? A realist review. Int J Qual Health Care. 2017 Oct 1;29(5):612-624. doi: 10.1093/intqhc/mzx095
- **4/** Vargas I, Mogollon-Perez AS, De Paepe R, Ferreira de Silva MR, Unger JP, Vazquez ML. Do existing mechanisms contribute to improvements in care coordination across levels of care in health services networks? Opinions of the health personnel in Colombia and Brazil. BMC Health Services Research (2015) 15:213. https://doi.org/10.1186/s12913-015-0882-4
- **5/** Ministry of Health and Long-Term Care. 7 Things you Need to Know about OHTs [webpage]. https://mailchi.mp/ontario/may-10-update?e=0c321e1d8d [Retrieved May 13th 2019].
- **6/** Ling T, Brereton L, Conklin A, Newbould J, Roland M. Barriers and facilitators to integrating care: experiences from the English Integrated Care

- Pilots. International Journal of Integrated Care. 2012;12(5):None. DOI: http://doi.org/10.5334/ijic.982
- 7/ Karam M, Brault I, Van Durme T, Macq J. Comparing interprofessional and interorganizational collaboration in healthcare: A systematic review of the qualitative research. International Journal of Nursing Studies, March 2018; 79:70-83. https://doi.org/10.1016/j. ijnurstu.2017.11.002
- **8/** Nutting PA, Crabtree BF, Miller WL, Stange KC, Stewart E, Jaen C. Transforming physician practices to patient-centred medical homes: Lessons from the National Demonstration Project. Health Affairs, 2011; 30(3): https://doi.org/10.1377/hlthaff.2010.0159
- **9/** Ham C and Walsh N. Lessons from experience. Making integrated care happen at scale and pace. The King's Fund: United Kingdom. 2013. https://www.kingsfund.org.uk/sites/default/files/field/field\_publication\_file/making-integrated-care-happen-kingsfund-mar13.pdf
- **10/** Rocco P. Contextualizing co-production of health care: a systematic literature review. International Journal of Public Sector Management, 2016; 29(1):72-90, https://doi.org/10.1108/IJPSM-07-2015-0125

### APPENDIX: SCENARIOS

The following two scenarios are presented in the practice guide for patient and caregiver engagement and illustrate a real-world example of what it looks like when the needs and preferences of the patient and caregiver are understood and addressed versus not.



### Poor outcomes

Needs and preferences of patient and caregiver are NOT understood or addressed.

### One day...

Mrs. Lee woke up feeling unwell. She's an 87-year-old widow and lives alone in her apartment. Her daughter, Laura, just returned from a short vacation and tries to reach her Mom by phone, and after several tries there is no response. She drives over to check on her. When she arrives, her Mom appears confused and tells her daughter that she feels dizzy.

There have been several coordinators involved in her Mom's care and she is unsure who to contact. She doesn't feel comfortable calling the primary care doctor directly so she calls 911 and her Mom is taken to the emergency room where she waits for several hours. Laura and her mother meet with several people where they have to repeat their story over and over again.

They decide to keep her overnight to run tests. Due to a lack of rooms she is in a stretcher in a hallway where it's noisy and unfamiliar. Laura is exhausted and frustrated at the lack of timely response to her Mom's needs. Her Mom is scared and eats very little, making her feel increasingly tired and weak. She misses another dose of her medication as she waits and is feeling increasingly dizzy.

On her way to the washroom she has a fall and fractures her hip and is now waiting for surgery. Given the lack of operating rooms she waits for several days and then catches pneumonia which further delays her surgery. Laura, the sole family caregiver is exhausted, confused, frustrated and takes several days off work without pay so she can be there to advocate for her Mom who doesn't speak English.

### APPENDIX: SCENARIOS

The following two scenarios are presented in the practice guide for patient and caregiver engagement and illustrate a real-world example of what it looks like when the needs and preferences of the patient and caregiver are understood and addressed versus not.



### Good outcomes

Needs and preferences of patient and caregiver are understood and addressed.

### One day...

Mrs. Lee woke up feeling unwell. She's an 87-year-old widow and lives alone in her apartment. Her daughter, Laura, just returned from a short vacation and tries to reach her Mom by phone, and after several tries there is no response. She drives over to check on her. When she arrives, her Mom appears confused and tells her daughter that she feels dizzy.

Their care coordinator, Sandra, whom Mrs. Lee and Laura have gotten to know quite well over the years, always encourages them to call if they need something. Mrs. Lee doesn't feel comfortable asking for help, but her daughter knows to contact Sandra when something is wrong. She rings Sandra and she answers quickly and listens to Laura's concerns. During this phone call her Mom starts to feel better but is very tired.

Sandra is in regular contact with Mrs. Lee's primary care team and is able to arrange a home visit with her primary care provider that afternoon. During the home visit Mrs. Lee has her vitals checked and blood work done and later it's determined that she needs to adjust her medication. The primary care doctor calls the pharmacy and arranges for the new medication to be dropped off.

During this visit it's also clear that Laura is feeling burnt out and is concerned about leaving her Mom alone for long periods of time during the day while she is at work. The primary care doctor shares this with Sandra who connects back with Laura to tell her about a Day Program that caters to the Chinese population. Since the day program is with her Chinese speaking peers, Mrs. Lee agrees to go, and her daughter, who gets to know the staff, feels comfortable knowing that her Mom is happy and safe. Attending the program also helps Mrs. Lee feel independent as she does not want to move into a long-term care facility.



### 4 PRACTICE GUIDE SUMMARY

### How can patient and caregiver needs be met by collaborative governance?

In this practice guide we describe how senior managers, clinical leaders and boards of directors can effectively collaborate with other organizations working together in an integrated model of care. We describe the "outward" and "inward" components of governance, and present collaborative governance as a strategy to enable good governance of integrated care.

### What is the difference between outward and inward governance?

Outward governance refers to the governance decisions of an organization that influence how the organization relates to its environment. This includes performance reporting to funders, and also engagement of community members to ensure services actually meet community needs.

Inward governance refers to the governance decisions of an organization that influence how well the organization performs. This includes processes related to internal decision-making and risk management.

### What is collaborative governance?

Collaborative governance is an approach to governance in areas where organizations need to work closely together in order to achieve their goals. Collaborative governance involves respecting the circumstances in which collaboration takes place, committing to face-to-face meetings to establish trust, and respecting a process that all parties agree upon for making collaborative decisions.

By responding to a series of questions informed by collaborative governance, organizations can orient their governance activities in a more collaborative way for more integrated care.

### What are the 3 key takeaways?

Integrated care demands a new approach to governance, where organizations focus on collaborative governance that explicitly acknowledges the challenges and opportunities of governing multiple organizations under a single structure.

The most important consideration for establishing collaborative governance is the establishment of a shared vision that all collaborating members can support. This requires investing in face-to-face discussion and understanding the experiences and perspectives of collaborators with empathy.

Governance structures and processes are subject to a learning process just as much as the skills of clinical collaboration. It takes time to develop governance structures and processes that work well for integrated care, and boards of directors should enable their collaborators to implement more integrated approaches to service delivery while constantly revisiting governance over time.

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# How can patient and caregiver needs be met by

# COLLABORATIVE GOVERNANCE?

### INTRODUCTION

### Why this is important

Experienced leaders know that good governance is an important foundation for high-performing organizations, especially in times of change. In an environment as complex as health care, governance becomes all the more important. How should government policies be interpreted when the tools used to deliver health care are evolving so rapidly? What kind of performance management approaches should organizations use when promoting innovation through collaboration? These are just two examples of the questions that help to define governance for integrated care, and will become important parts of the effort to help organizations develop strong and sustainable collaborations. Meaningful progress on integrated care requires a new approach to governance that emphasizes collaboration at the highest level. Figuring out how to establish such collaborative approaches to governance is the focus of this practice guide.

One important point to note at the outset is that governance for integrated care means the governance of collaborations, not the governance of individual organizations. Although organizations are involved, and governance decisions about integrated care will affect individual organizations, the challenge is to think about how to govern a group of organizations working together to deliver better care.

Governance is a slippery concept, and even a brief look into research on the topic will show a variety of definitions and best practices (Stoker, 1998; Rhodes, 1996). One point that is consistent across research on governance is that even in environments where regulation by government policy is strong (such as in health care), the role of individual organizations, organizational leaders, and boards of directors continues to become increasingly important (Tuohy, 2003).

This is because there is a broader, long-term shift underway toward increasing the role and responsibility of non-governmental organizations in the delivery of public services, which have historically been the responsibility of governments (Tuohy, 2003). Government of course still plays an important role, but the roles of organizations that are independently owned and operated such as health care delivery agencies are becoming increasingly important to the future of health care (Pyone, 2017).

In that spirit, the importance of governance in the effort to implement integrated care becomes clearer. Many boards of directors and organizational leaders will need to think differently about how they view concepts such as accountability and performance management in order to enable their staff and collaborators to achieve care that resonates with the "when things work well for Mrs. Lee" scenario. Good governance enables good management, and good management enables good care. In this practice guide, we outline why this is the case and describe the approach of "collaborative governance" that can best support the implementation of integrated care.

### **How this relates to Ontario Health Teams**

For the effort to develop Ontario Health Teams (OHTs), collaborative governance for integrated care means bringing organizations across the continuum of care together to think about a single vision and a shared governance structure that makes sense in Ontario's health system. Each organization involved in an OHT will have its own longstanding governance structure, and that remains important. However, it is the ways in which leaders can bring organizations together to make decisions that matter for all those involved that will be most important. And that requires establishing an approach and a structure for how organizational leaders (e.g., senior management and boards

of directors) will make shared decisions related to issues such as sharing government funding, agreeing on strategic directions, and solving problems that affect more than one organization involved.

For the effort to build OHTs, face-to-face meetings between leaders from collaborating organizations will be an essential first step in the effort to build the trust on which collaborative governance so clearly depends. This is the primary way in which leaders can take meaningful steps toward building a shared vision that truly respects the histories and capabilities of each organization involved. In so doing, organizations can develop and agree upon a process for coming together to make decisions that can be respected by all parties. This process will help to protect the integrity of shared work and support a sustainable approach to collaborative governance for OHTs.

### INSIGHTS

### What we know about governance in health care

Governance refers to the agreements made among members of an organization or a collaborative group about decision-making, risk-taking, and financial responsibility (Klein et al., 2019). This definition focuses on the individual organizations that make up the health and social care system, which is an important starting point for a discussion on the governance of collaborations involving multiple organizations. In our case, this means health care delivery agencies that may span a broad continuum of health and social care, including community support services. We will refer to all of these agencies collectively as "health care delivery organizations".

As the responsibilities of delivery agencies have grown in health care, governments have required more explicit accountability for performance (Addicott and Shortell, 2014). Performance reporting can simply be a matter of reporting the specific services that are delivered by a given organization to a funder, but this is increasingly shifting to reporting on the ability of organizations to meet certain quality standards (Porter, 2009). A second form of accountability is the accountability of health care organizations to the communities they serve. The growing trend of including patients and other community members more fully in governance processes represents this important development, and is a crucial component of governance for integrated care. We refer to these kinds of accountability as "outward governance", indicating that they relate to the relationship between an organization and groups to which organizations are accountable outside of their boundaries.

A second important element of organizational governance relates to the general responsibility for the wellbeing of the organization. This means that there needs to be sufficient oversight related to the

development of strategy, the operational approach, and the financial responsibility that represent the organization's activities. This component of governance includes the development of strategic and performance management approaches related to collaborative care delivery. We refer to this kind of governance activity as "inward governance", relating primarily to the activities of the organization in order to successfully deliver health services.

Governance represents both a structure and process that links an organization to the larger environment, responding to the needs of its community and building on the strengths if its stakeholders. Where organizations intend to develop formal collaborations for integrated care, they will need a new approach to governance that enables the group to achieve these important goals. In so doing, teams will establish both outward and inward approaches to governance in new ways. This new approach to governance will clarify the roles of the organizations involved, their relationships to one another, and how they will view both "outward" and "inward" governance responsibilities. The challenge is to apply the insights that have been

## What is the difference between outward and inward governance?

### 1/ Outward governance

The governance decisions that influence how an organization relates to its environment.

### 2/ Inward governance

The governance decisions that influence how well the organization performs.

developed about organizational governance to the collaborative group. Here is where the notion of "collaborative governance" becomes central.

### Collaborative governance and integrated care

Research on the governance strategies used during the implementation of integrated care elsewhere in the world shows the challenges associated with governing integrated care. In the United States, a study of the governance strategies that emerged for Accountable Care Organizations (ACOs) found that clinicians were highly involved in the governance of the newly formed collaborative organizational structures, but that there was very little evidence of truly shared accountability across organizations that might be expected with a shared funding envelope (Addicott and Shortell, 2014). In a very different policy setting, research in Quebec has documented the multiple strategies and persistent challenges of developing meaningful collaboration between organizations in an environment where collaboration was "mandated" by policy (Rodriguez et al., 2007; Touati et al., 2019). These and other experiences internationally illustrate the importance of paying close attention to how approaches to organizational governance will need to evolve in order to promote the success and sustainability of new models of more collaborative approaches to integrated care.

Collaborative governance is an idea that represents the efforts of organizations to work together when making decisions about how to implement programs that relate to the public interest (Ansell and Gash, 2008). Although much research on collaborative governance has focused on getting collaborations started, the approach also has much to say about sustaining ongoing collaborations that involve stakeholders both inside and outside of government. Table 1 provides an overview of collaborative governance and its relevance to implementing integrated care (see Ansell and Gash, 2008 for more information). This overview

of collaborative governance forms the foundation for the more specific guidance on governance for integrated care we provide next.

### Making collaborative governance happen

The work of establishing a new model of integrated care requires organizational leaders to come together to build a new governance structure that represents the collaboration of the contributing organizations. But there is no single best governance structure that can apply across all health care environments and many collaborative governance structures develop over time with the growth in knowledge and trust between partners. Thus seeking the "ideal governance approach" may actually pose barriers to progress.

### What is collaborative governance?

An approach to governance in areas where organizations need to work closely together in order to achieve their goals.

### It involves...

- 1/ Respecting the circumstances in which collaboration takes place
- 2/ Committing to face-to-face meetings to establish trust
- 3/ Respecting a process that all parties agree upon for making collaborative decisions

Governance will evolve as the integrated model of care evolves. Having a clear, well-articulated and transparent process for developing and revisiting the governance model should be a primary focus. It is more important to have a process for coming together to build, discuss, and revise the governance structure than it is to get governance perfect on the first try. Establishing this process and identifying people to champion the process are the most important first steps. The process and structure of governance for integrated care will evolve over time.

Making collaborative governance work for integrated care requires close attention to detail and a relentless focus on relationships. We outline some questions in detail that can help to establish a collaborative governance approach for integrated care in Table 2. Board members and organizational leaders should reflect on these questions as they embark on the effort to establish new models of integrated care. After independently thinking through these questions, facilitated face-to-face group discussion will help to establish shared understanding. This shared understanding is a fundamental step in the effort to successfully establish new models of integrated care.

One point worth emphasizing at the outset is the importance of establishing a shared vision for what the emerging model of integrated care should look like. A shared vision relates not only to the principles that each partner will abide by when engaging in collaborative activity, but also the ultimate design of the integrated service that patients and caregivers will experience during health care encounters. A vision for the service includes a clear statement about which providers are involved, their lines of communication, and the ways in which patients will move through the model. Governance decisions will need to be made collaboratively related to each of these important points.

### Table 1/ The five collaborative governance dimensions for integrated care.

(see Ansell and Gash, 2008 for more information)

### **Dimension 1**

## Starting conditions

The history of the relationships between organizations, and individuals representing those organizations, indicate the starting point for engaging in collaborative governance.

Positive relationships enable shared understanding, and less positive relationships must be improved before collaborative governance can proceed.

### **Sub-dimensions**

### 1/ Power/resource imbalances

Some healthcare organizations, such as hospitals, have historically had greater resources and influence than others. Integrated care initiatives must acknowledge these imbalances in building trust and shared understanding.

2/ A shared vision and goals are prerequisites for success

### 3/ Incentives to participate

Even when partnering organizations share goals in providing the best possible care for specific populations, existing or new incentives may have differential impact. Thus the particular incentives to participate in a new model of integrated care need to be made explicit. These incentives help to keep stakeholders committed to the collaborative governance process.

### 4/ Pre-existing history

Poor previous relationships can be difficult to acknowledge, but doing so can be an important first step in establishing mutual understandings. Acknowledging the past is essential when building collaborations, and will help to shape the elements of success partnerships.

### **Dimension 2**

## Institutional design

The basic protocols and ground rules for the collaboration need to be established as a first priority, and these are considered the "institutional design" for collaborative governance. This includes determining which stakeholders will be included in the governance process.

### **Dimension 3**

## Facilitative leadership

A clearly defined leader or small group of individual leaders can emerge organically or may be assigned at the outset. A leader who is facilitating collaborative governance focuses on respecting the process of establishing and sustaining the collaboration, not on the interests of any given party.

### **Dimension 4**

## Collaborative process

Clear process is essential to collaborative governance, and relies on establishing trust and shared understanding.

This is grounded in face-to-face contact, and benefits from establishing intermediate goals that can demonstrate early successes.

### **Sub-dimensions**

### 1/ Face-to-face dialogue

Meeting in person will help build trust and clarify shared goals for collaboration in an integrated care initiative.

### 2/ Trust-building

Particularly in situations where there is a preexisting history of antagonism, sufficient time needs to be budgeted to build trust across organizations (and across sectors of health and social care).

### 3/ Commitment to the process

Where all stakeholders commit to the processes that characterize collaborative governance, all parties can be assured that they will have an appropriate voice in the eventual approach to governance agreed upon by the group.

### 4/ Shared understanding

Although the common goal of improving the health of a population of people will be clear at the outset, achieving this goal is made up of a number of sub-goals. Gaining clarity on what those sub-goals are, and how each stakeholder will contribute to achieving them, are key activities for collaborative governance of integrated models of care.

### 5/ Intermediate outcomes

Based on agreement over what the subgoals of the collaborative group are, and how those goals will be achieved, the group can establish intermediate outcomes and commit timeframes to achievement. These outcomes help illustrate the progress made by the group, and make course corrections as necessary respecting the timeliness needed.

### **Dimension 5**

### Outcomes

The desired results of collaborative activity, in this case represented by enhanced outcomes for the population served by the model of integrated care.

### Table 2/ Guiding questions for a collaborative governance approach to integrated care

(see Ansell and Gash, 2008 for more information)

## Establishing a process for collaborative governance

## Q1/ How will you decide which organizations get to participate in the collaboration? Is the full continuum of care represented?

This might require unconventional thinking, as effective integrated models often include a broad spectrum of health and social services.

It will be important for all involved organizations to be committed to achieving some consensus, especially around a shared vision for the goals of the integrated model of care.

### **Q2/** How will imbalances in resources be acknowledged and addressed?

Smaller organizations are unlikely to have the human resources to devote to efforts such as quality improvement and advanced data analysis, or even governance development. They may also be under-resourced to deliver services. Acknowledging these differences is important to building trust, and to addressing challenges that might be important in the delivery of more integrated care.

## Q3/ How will you decide which organization takes on which responsibilities in the collaboration?

There are a number of things to consider when making this decision, including the past performance of an organization, the circumstance of its past performance, and its plan to develop in the future.

These decisions will also require a clearly understood starting point for which services will be offered in the integrated model of care. Importantly, there needs to be a provision to address governance for services that may evolve over time.

## Q4/ How will you decide the reporting relationships between organizations involved in the integrated model of care?

Clearly defined roles and responsibilities include well-defined accountability relationships. What exactly is each organization responsible to accomplish, and how will they be held accountable?

### Q5/ What goals will frame the collaboration? How do these relate to a shared vision?

Establishing a shared vision about the activities of the integrated model of care is essential to guiding management activity.

Goals should include both short-term realistic goals and more aspirational long-term goals. Being able to demonstrate "quick wins" is an important part of motivating collaborating organizations to commit and remain committed. Governance needs to address the continuing health of collaboration.

## Q6/ How do you ensure strong representation of clinical groups in leadership and governance?

The close involvement of health and social care provider representation in governance decisions is essential for broad clinician buy-in. Clinicians represent the expertise of health care delivery that can support new models of integrated care in achieving excellence in services.

### Q7/ How will patient and caregiver engagement be built into governance decision-making?

Patient and caregiver engagement is an essential element of more integrated models of care, and

many successful integrated care initiatives have the direct input of patients and other community members in board-level decision-making processes. Determining a strategy for continuously engaging patients and other community representatives in decision-making for the integrated model of care, and how that input will relate to the collaborative governance approach, will be essential.

## Making "inward governance" decisions

## Q1/ Which management and administrative roles from the collaborating organizations will be involved in determining the approach to managing the integrated model of care?

Managers will serve important roles related to supporting a collaborative approach to care delivery, maintaining interest from collaborating members, and solving conflict where it arises. These expectations need to be clearly stated in their job expectations.

### **Q2/** How will decisions related to branding be made?

A brand should reflect the shared vision of the collaborating organizations, and will be important for promoting the integrated program as a whole.

### Q3/ How will decisions about information technology and information sharing be made?

Digital tools are increasingly important to the delivery of integrated care, and information sharing within the boundaries of personal privacy and data security is central to a progressive service collaboration. Specific governance and security protocols approved at the governance level need to identify how health care providers are able to

access information documented by collaborating organizations.

### Q4/ How will risks encountered in the process of providing effective care be managed?

Serving people with complex needs requires creativity and a willingness to solve problems. This means that providers and organizations will need to take reasonable risks related to interventions that can meet individual needs. An example would be putting risk mitigation strategies in place in order to support an early discharge from hospital. Having a strategy in place to support decision-making and account for those acceptable risks will be an important component of the governance strategy.

### Q5/ How will conflicts be resolved?

Conflict may occur between organizations, between providers, or at the level of patient encounters. A general approach to resolving these conflicts should be agreed upon in advance and will require transparency to be meaningful within the collaborative context.

## Q6/ Who will be responsible for ensuring the financial responsibility and viability of the collaborative activities?

The organizations involved will need to commit time and energy to getting the integrated model of care fully operational, which will require various and significant amounts of in-kind contributions. These start-up costs and efforts are important investments for the integrated model of care, and will need to be fully accounted for when thinking about the management and sharing of costs.

Financial management of a collaborative group requires unique skills and an open approach to the governance of fiscal responsibility. An acceptable approach will depend on extensive trust-building between key people at the collaborating organizations.

## Making "outward governance" decisions

## Q1/ Which metrics will determine the quality of the performance of the integrated model of care?

Certain metrics will be decided by government oversight, but others will be determined by the organizations involved. Deciding who is responsible for measuring and monitoring these metrics is an important component of governance.

An important element of governance responsibility includes making meaningful information available to the broader public community.

### How will you know if this is working well?

Collaborative governance is a challenge, particularly in industries as complex as health care. However, there are ways to gauge progress in achieving a collaborative approach to governance, and we present a working start in the exercise "Is it working well?" at the end of this guide.



### Three key takeaways

Integrated care demands a new approach to governance, where organizations focus on <u>collaborative</u> governance that explicitly acknowledges the challenges and opportunities of governing multiple organizations under a single structure.



The most important consideration for establishing collaborative governance is the establishment of a shared vision that all collaborating members can support. This requires investing in faceto-face discussion and understanding the experiences and perspectives of collaborators with empathy.



Governance structures and processes are subject to a learning process just as much as the skills of clinical collaboration. It takes time to develop governance structures and processes that work well for integrated care, and boards of directors should enable their collaborators to implement more integrated approaches to service delivery while constantly revisiting governance over time.

### EXERCISE: IS IT WORKING WELL?

Rate how well your organization is doing on the following dimensions of collaborative governance [1 represents poorer performance and 5 represents better performance]. Responses should serve as an opportunity for reflection and improvement in governance processes. After completing your response on each item, choose one area of focus and establish a plan for making improvements with leaders from collaborating organizations. Once satisfied with your progress, select another item, and repeat.

			canding of Ited model		stakeholde	r gro	up views the effor
	Not well		2	3		5	Very well
2/ We have discussed together any challenges perceived by each stakeholder group.							
	Not well		2	3	4	5	Very well
3/ We have face-to-face meetings regularly occurring throughout the course of a year.							
	Not well		2	3	4	5	Very well
4/ We have principles or guidelines in place to protect the integrity of the collaborative process.							
	Not well		2	3		<b>D</b> 5	Very well
5/ We have a clearly identified leader or leaders who are responsible for the collaborative process, over and above their responsibility to their own organizational goals.							
	Not well		2	3		5	Very well
6/ All members of the collaborative group understand the goals of the integrated model of care.							
	Not well		□ 2	3		<b>D</b> 5	Very well

### REFERENCES

- 1/ Stoker G. Governance as theory: five propositions. International social science journal. 1998; 50(155):17-28.
- 2/ Rhodes RAW. The new governance: governing without government. Political studies. 1996; 44(4):652-67.
- 3/ Tuohy CH. Agency, contract, and governance: shifting shapes of accountability in the health care arena. Journal of health politics, policy and law. 2003; 28(2-3):195-216.
- **4/** Pyone T, Smith H, van den Broek N. Frameworks to assess health systems governance: a systematic review. Health Policy and Planning. 2017; 32(5):710-22.
- **5/** Klein PG, Mahoney JT, McGahan AM, Pitelis CN. Organizational governance adaptation: Who is in, who is out, and who gets what. Academy of Management Review. 2019; 44(1):6-27.
- **6/** Addicott R, Shortell SM. How "accountable" are accountable care organizations? Health care management review. 2014; 39(4):270-8.
- 7/ Porter ME. A strategy for health care reform—toward a value-based system. New England Journal of Medicine. 2009; 361(2):109-12.
- **8/** Rodriguez C, Langley A, Béland F, Denis J-L. Governance, power, and mandated collaboration in an interorganizational network. Administration & Society. 2007; 39(2):150-93.

- **9/** Touati N, Maillet L, Paquette M-A, Denis J-L, Rodríguez C. Understanding Multilevel Governance Processes through Complexity Theory: An Empirical Case Study of the Quebec Health-Care System. International Journal of Public Administration. 2019; 42(3):205-17.
- **10/** Ansell C, Gash A. Collaborative governance in theory and practice. Journal of public administration research and theory. 2008; 18(4):543-71.



