

# Implementation of an Agency to Improve Chronic Kidney Disease Care in Ontario: Lessons Learned by the Ontario Renal Network

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## Abstract

**In 2009, Ontario's Ministry of Health and Long-Term Care initiated the transfer of oversight and coordination of chronic kidney disease (CKD) care to the Ontario Renal Network (ORN) under the auspices of Cancer Care Ontario (CCO). The aim was to replicate the quality improvement and change management practices used for cancer control within CKD. Much of the ORN's first three years were dedicated to building the infrastructure necessary to bridge the gap between provincial policy and clinical practice. This article explores the accomplishments, challenges and lessons learned over that period. The results, which are applicable to the management of chronic diseases in Ontario, Canada, and internationally, confirm that sustainable change takes time and requires strong leadership, transparency, accountability and communication, supported by a solid foundation of data and evidence.**

## Introduction

Prior to 2009, the province's chronic kidney disease (CKD) care system had been administered by the Ontario Ministry of Health and Long-Term Care (MOHLTC). This system consisted of 26 regional CKD programs that included over 90 sites caring for approximately 10,000 dialysis patients. Demand for services was outstripping supply in a number of regions, system planning was fragmented, provincial data on disease prevalence and

quality of care were absent and provincial improvement efforts lacked clinical leadership. A number of reports called for a more coordinated and integrated approach, including the creation of a provincial data set and agency (Kidney Foundation of Canada 2008; MOHLTC 2004, 2006, 2009). In 2010, the MOHLTC transferred provincial oversight and coordination of CKD to the Ontario Renal Network (ORN) under the auspices of Cancer Care Ontario (CCO). This transfer was formalized through the MOHLTC–CCO–ORN Accountability Agreement. This Agreement established areas of accountability for the ORN, deemed essential to building a strong foundation for improvement:

- Provincial and Regional Program Management: Establish an Ontario leadership team within CCO to inform the strategic direction, manage the provincial office and align and support province-wide implementation of improvements for the management of CKD. Establish regional leadership to drive the provincial CKD program agenda in every local health integration network (LHIN) and to align and support regional implementation of CKD quality improvement initiatives across Ontario.
- Performance Measurement and Management: Implement a performance measurement and management cycle to track the success of activities and strategies, and to improve

CKD program accountability and performance.

- Information Technology: Implement a provincial information system for clinical program and CKD system planning, management and funding.
- Communications and Stakeholder Relations: Establish the ORN as a transparent and accountable provincial entity within CCO, and engage a broad coalition of CKD stakeholders in its work.

### **Provincial and Regional Program Management**

The ORN's initial leadership consisted of a provincial medical director (nephrologist) and an executive lead; these individuals were supported by a small CCO-based secretariat (four FTE). Late in 2010, a CCO vice president with system-level management and policy experience was appointed. During this time, the regional leadership comprised a paid regional director (RD) and a volunteer regional medical leader (RML) associated with each LHIN region.

In 2010, Adeera Levin, Executive Director of the British Columbia Renal Agency, conducted an internal review of the ORN to inform the leadership on the current state of functioning, opportunities and challenges after one year of operation (Levin 2010). This review found that the leadership and advisory structure did not resonate well with stakeholders, and a number of recommendations were made to improve engagement with CKD providers and stakeholders. As a result, an ORN Executive Committee and Advisory Council were formed, and the provincial leadership was expanded to include physicians accountable for the ORN's priority areas: Vascular Access; Independent Dialysis; Early Detection and Prevention; Funding; Research; and Data and Reporting (ORN 2012a).

In 2012, ORN undertook a second review focused on the ORN's regional structure (ORN 2012b). This review found that the regional leadership was focused on administrative issues and lacked consistency across all the regions; for example, the RDs had inconsistent roles, responsibilities and remuneration, with some RDs lacking operational responsibilities within a regional CKD program. Regional leadership is a critical component of the CCO improvement model because it requires change leaders to be formally accountable at both provincial and regional levels. The RMLs were not remunerated and were much less engaged. Since 2013, a revised RD role description and contract has been implemented to improve consistency, and all RDs have management responsibilities within a regional CKD program. Similar to their RD counterparts, since 2013, the RMLs have been remunerated for half a day a week to improve accountability at both the provincial and regional levels. The regional leadership meet regularly with the provincial office to improve engagement.

Through discussion with both provincial and regional leadership, it has also become apparent that while many RDs, RMLs and provincial leads have held local leadership positions (e.g.,

Renal Program Director, Chief of Nephrology), few have had experience with policy or change management across a system of providers and stakeholders. As a result, ORN and CCO have improved access to continuing education and training, implemented stronger orientation practices and established a Centre of Practice to improve physician leadership recruitment and development (CCO 2014).

### **Performance Measurement and Management**

In 2010, the first accountability agreements between the ORN and the 26 hospitals with regional CKD programs were established. As a condition of funding, these agreements set out expectations for service volumes, reporting and quality improvement. These conditions, along with regular meetings with the CKD programs, RDs and RMLs, form the foundation of ORN's Performance Improvement Cycle for CKD care

As a commitment to public reporting and accountability, ORN also publishes performance metrics on its website ([www.renalnetwork.on.ca](http://www.renalnetwork.on.ca)). Public reporting of performance was new to many CKD care providers and resulted in considerable confusion and concern regarding its purpose and motivation. More explicit and direct engagement of care providers regarding the components and purpose of the performance improvement cycle was needed. Another expectation of the Agreement was for ORN to develop and implement a funding framework that is patient-based, reflects best practice and achieves greater funding equity across the province. At the time of ORN's inception, regional CKD program funding was based on self-reported service volumes, with little connection to quality or outcomes of care. Development of a new funding framework was based on transparent application of clinical and financial data; advice by clinicians, administrators and policymakers at both a provincial and regional level; and CCO's experience with case-based funding.

Implementation of the new framework, now part of the MOHLTC's Health System Funding Reform (MOHLTC, 2013), was completed in 2014. This funding transformation was supported by numerous tools and documents (e.g., workbooks to assess financial impact and help with budget transition, guides to describe purpose, methods and all funded services) and is governed by a panel representing ORN Provincial Office, RDs and RMLs (ORN 2014). Evaluations during implementation indicated that this approach was well-received by the regional CKD programs. Funding for CKD is being expanded in 2014 to include home and long-term care.

### **Information Technology**

Foundational to ORN's work is its ability to transform data into information useful for decision-making. In 2010, the Ontario Renal Reporting System (ORRS) was launched to provide timely data for CKD planning, funding and performance/quality reporting. Administered and managed by the

ORN Provincial Office, the ORRS collects data on all persons receiving dialysis and pre-dialysis care in Ontario. Essential to quick implementation of the ORRS was CCO's existing information management/information technology infrastructure, along with CCO's status as a prescribed entity within Ontario's Personal Health Information Protection Act (Service Ontario 2014). Regular enhancements to the ORRS continue, such as the roll out of direct access to the ORRS by each CKD program to improve data quality and disease monitoring and management at a local level (ORN 2014). Along with performance measurement, the ORRS and CCO's data analysis capacity was essential for the creation of an annual review of renal system capacity – another key deliverable in the Agreement. Based on the best available evidence, and developed in collaboration with the Institute for Clinical Evaluative Sciences (ICES), the Centre for Research in Healthcare Engineering and CKD programs, this review represents a shared understanding of the supply of and demand for dialysis services at a provincial and local level, and serves as a guide for future capital investment (ORN 2014). The most recent assessment includes capacity needs up to the year 2024, and was expanded beyond dialysis to include vascular/body access services and inpatient care.

### **Communication and Stakeholder Relations**

Since its inception, the development of a communications plan for regional CKD programs and physicians has been an important undertaking for ORN (Levin 2010). Initiatives such as the funding framework implementation, capacity assessment development and ORN Annual Planning Day continue to reinforce the need for intensive communication with stakeholders using a variety of methods such as newsletters, email, social media and meetings. A key feature of the ORN model has been to involve physicians in the management of renal care in Ontario. Historically, there had been a degree of distrust between the MOHLTC and nephrologists in the province. The introduction of physician co-management has helped to resolve this. Paid and accountable provincial and regional medical leads, the presence of four nephrologists on the ORN executive team and extensive nephrologist involvement in funding policy, organizational and clinical standards development and strategic planning initiatives have given physicians a central role in ORN governance. These changes mark a radical shift in the model of renal care delivery in Ontario.

### **Building on the Core Elements to Improve Quality**

In May 2012, ORN released the *Ontario Renal Plan*: the first comprehensive roadmap for CKD care in Ontario (ORN 2012a). Developed through consultation with the MOHLTC, CCO, LHINs, regional CKD programs and CKD organizations such as the Kidney Foundation of Ontario, the plan describes

our strategy to address the burden of end-stage renal disease, while improving the quality of care and treatment of current and future CKD patients. Framed by IHI's Triple Aim (Institute for Healthcare Improvement [IHI] 2014), seven priority areas (each with explicit targets) are described in the plan:

- Accountability to patients (AP)
- Early detection and prevention of progression (EDPP)
- Peritoneal and vascular access (VA) for dialysis patients
- Home or independent dialysis (ID)
- CKD infrastructure planning
- Research and innovation (RI)
- Funding aligned with quality patient-focused care.


Progress on these priority areas has been variable. As described earlier, funding and infrastructure planning have been successfully delivered and continue to be refined. For ID and VA, care coordinators have been established in every CKD program, an IHI-type collaborative (IHI 2003) has been implemented to support the coordinators along with provincial and regional leadership and information tools to track patient progress have been implemented. As a result of these activities, the proportion of dialysis patients using a home modality has begun to increase. However, a lack of consensus exists among nephrologists regarding the appropriate use of fistulas, compounded by issues of access to surgical care. As a result, a reduction in the percentage of haemodialysis patients using catheters has not yet been achieved. Improved data reporting has been implemented to study and improve issues of appropriateness, surgical access and performance

For EDPP, ORN initiated primary care practice pilots and partnered with the Electronic Medical Record Administrative Data Linked Database (EMRALD) project at ICES to evaluate CKD identification and management tools associated with their electronic medical records. As well, the EMRALD project will evaluate the effectiveness of performance scorecards for improving the management of chronic diseases by primary care (ICES 2014). To further support primary care, ORN has developed a CKD management algorithm and a standard referral form, and has carried out mentorship pilots that linked primary care providers to nephrologists for education and timely advice. Evaluation of the pilots demonstrated the need for greater peer support of primary care providers by their nephrology colleagues, as well as regular primary care educational opportunities (Cathexis 2014)

The RI and AP portfolios were slower to develop, but have made more recent progress. ORN is partnering in a number of research agencies to fill critical information gaps and with CCO has undertaken a corporate review of its research program to assess how we can better support CKD research needs. Under the guidance of CCO's Centre of Practice for Patient and

Family-Centred Care, ORN has begun to regularly and extensively engage patients and families in strategic and operational planning and will soon launch a provincial Patient and Family Advisory Council.

## Summary

ORN was created to plan and manage CKD system resources to ensure that high-quality care is available to those who need it, when and where they need it. As the system steward, ORN had to effectively bridge the gap between provincial policy and clinical practice. Bridging this gap required the implementation of numerous structures and processes. Provincial and regional leadership was required to define best practices and to champion these practices with front-line care providers. Valid, reliable and comparable data were required to measure performance and establish greater accountability. Methods for transparent communication and decision-making among the providers, policymakers and planners were launched to build trust and a shared purpose – the continuous improvement and sustainability of CKD care. ORN's progress towards goals and objectives identified in the first Ontario Renal Plan is evidence that numerous bridges have been successfully constructed. The second Ontario Renal Plan, due for release in the spring of 2015, will identify strategies to continue this progress as well as set out additional goals to improve the lives of all CKD patients and their families. 

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ORN is a network. The early days were driven by a few dedicated people, but the concept only really began to take form when the linkages among a diverse and multidisciplinary group of administrators, providers and patients took hold. Thus, while this paper was written by a few, the successes it documents are the result of many. While we would love to name them, this runs the great risk of forgetting someone. Thanks to all of you for your dedication to improving the care of persons with CKD.

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