

# A report on establishing a network of multidisciplinary chronic kidney disease clinics across Canada

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# An introduction to CANN-NET (CAnadian KidNey KNowledge TraNslation & GEneration NeTwork)

Patients with chronic kidney disease (CKD) do not always receive care consistent with guidelines, in part due to complexities in CKD management, lack of randomized trial data to inform care, and a failure to disseminate best practice. The Horizon's 2015 meeting (a conference of key stakeholders in kidney disease) in 2008 highlighted the existing gap between best evidence and practice in Nephrology. It was also noted that the impact of Canadian Society of Nephrology (CSN) guidelines was attenuated given limited formal linkages between the CSN Clinical Practice Guidelines Group, kidney researchers, and relevant knowledge users (including leads of renal programs across Canada). The concept for CANN-NET arose from this meeting. With funding from the Canadian Institutes of Health and the Kidney Foundation of Canada, CANN-NET was developed in partnership with the CSN to improve the care and outcomes of patients with CKD.

Initial CANN-NET priorities are based on an assessment of gaps in the care of people with kidney disease, supplemented through a survey of heads of Canadian Renal Programs to determine priorities for new clinical practice guidelines and knowledge translation activities. A selection of the top priorities were finalized at a face-to-face meeting of knowledge users in March 2011, and included **timing of dialysis initiation** and **increasing appropriate use of home dialysis**. Updated CSN guidelines have recently been completed to guide care with respect to timing of dialysis initiation.

### The rationale for establishing a network of Canadian Multidisciplinary CKD Clinics

In the past, there have been no formal links between Canadian kidney disease guideline producers and the health care professionals who will put those guidelines into practice ('end users', i.e. physicians, nurses, renal programs, patients and others involved in the care of people with kidney disease). CKD clinics are often the entry point of many patients to dialysis care. Since key priorities of CANN-NET included dialysis initiation and modality selection, two activities which are closely linked to CKD care, it was important to improve understanding of the functioning of these CKD clinics, and understand their role in the context of patient preparation for and initiation to dialysis. The long-term goal of CANN-NET is to improve the understanding of CKD care, and one way to facilitate this is to develop a **network of key contacts at multidisciplinary CKD clinics across Canada**. As a preliminary step towards this, we surveyed CKD clinics across Canada to understand more about current care, and resources within these clinics.

#### How we surveyed CKD clinics

We initially contacted the nursing, administrative or medical leads (or the most relevant contact) for all renal programs across Canada (by email or phone). We collected contact information for local nursing and medical leads and/or clinic managers for all multidisciplinary CKD clinics across Canada who care for patients with kidney failure approaching the need for dialysis or transplantation.

Starting in June 2012, two CANN-NET knowledge translation brokers conducted telephone surveys to establish an up-to-date network of contacts for CKD clinics as well as collect general information on existing CKD clinic structure (including available resources, the model or care, education resources, use of clinical pathways, etc). Information was collected using semi-structured, open-ended questions (Appendix 1). The information collected is kept confidentially and centers will not be identified in reports.

# **Preliminary findings**

#### Sample

As of November 15 2013, a total of 71 multidisciplinary CKD clinics across Canada have been contacted and interviewed. Of the 71 completed surveys, 23 were in Western Canada, 27 in Ontario, 11 in Québec, and 10 in the Atlantic Provinces (Figure 1). Of the 71 surveys approximately  $1/3^{rd}$  were with medical leads (physicians), while the remainder was done with nursing or administrative CKD clinic managers.

CKD Clinics cared for between 26 and 2700 patients, and were staffed with between 1 and 33 nephrologists. Of interest, the staffing ratio of patients to nephrologist ranged from 26 to 450 across the clinics (Figure 2). The staffing ratio of patients to CKD clinic nurses also varied from 9 to 900 (Figure 3). Almost all clinics (67/71) employed dietitians, 50/71 employed pharmacists and 65/71 clinics employed social workers (see Figures 4, 5, and 6).

Of the clinics that reported having eGFR referral criteria<sup>1</sup>, namely 35/71, or 49% (Table 1), the majority (25/35, or 71%) indicated that the patient's eGFR would have be <30ml/min/m<sup>2</sup>. The remaining indicated that the eGFR referral range was between 30 and 60 ml/min/m<sup>2</sup> (14%).

#### Dialysis modalities provided and modality education

All clinics operated within the context of a renal program that offered in-center hemodialysis (99%), and nearly all programs offered peritoneal dialysis (94%), home thrice weekly hemodialysis (66%), and home nocturnal hemodialysis (73%). Daily in-center hemodialysis, self-care in center hemodialysis, and in-center nocturnal hemodialysis were offered less frequently (Figure 7).

 $<sup>^{1}</sup>$  Of the 35 clinics, 25 indicated the eGFR referral criteria were <30ml/min/m $^{2}$ , 5 indicated a range of 30 to 60ml/min/m $^{2}$ , 2 indicated eGFR referral criteria was <60ml/min/m $^{2}$  and 3 clinics did not answer the question.

73% of programs (52 CKD clinics) had a policy in place whereby all patients were assessed for home dialysis (Table 1). Of the remaining 19 CKD clinics, only one program did not offer home dialysis. The rest of the CKD clinics indicated that patients were assessed for home dialysis even though no policy was in place per say. While all programs noted that they offer dialysis modality education, 41% offered this during clinic visits or through distribution of educational materials alone, while 59% offered group dialysis modality education. Only 32% of programs employed a dedicated dialysis modality coordinator, though programs noted that individual CKD clinic nurses often filled this role (Table 1).

With respect to home dialysis targets, 73% of programs noted that their renal program operates within an environment where they are aware of a target for home dialysis use (Table 2). For 42% of these programs, the target is based on the proportion of prevalent home dialysis patients, while for 48% there is a target for both incident and prevalent home dialysis use. A small percentage (6%) was aware of targets specifically aimed at incident home dialysis use.

## Timing of dialysis initiation

25 clinics (35%) stated that eGFR levels alone generally led to dialysis initiation in out-patients with progressive CKD, but clinics often noted that other factors, including symptoms, were important in the decision to initiate dialysis.

Of the 25 clinics noting that an eGFR level was important on its own in leading to dialysis initiation, 40% (10) stated a threshold level of <10 mls/min/ $m^2$ , while 20% (5) stated a threshold level of 10-15mls/min/ $m^2$ . An additional 8 clinics indicated dialysis was sometimes initiated above 15mls/min/ $m^2$ . Two clinics did not answer the question.

As expected, nephrologists were felt to have the main role in the decision-making process of when to initiate dialysis. Only 38% of CKD clinics currently have a multidisciplinary team meeting where the timing of dialysis initiation is discussed (Figure 8).

# Model of patient care within the CKD clinic

The majority of patients (58%) were managed by the same nephrologist and the same nurse within CKD clinic visits. A small percentage (12%) of patients would see a different nephrologist and a different nurse at each visit (Figure 9).

We are trying to get doctors to refer

"We are trying to get doctors to refer their kidney disease patients earlier. Currently many don't refer their patients to the CKD clinic until their eGFR is around 18, which makes it much harder to stabilize and treat them".

#### **Challenges and improvements**

Respondents provided their opinions on where improvements could be made to improve patient outcomes. The most common issues that were raised included that more staff, space and improved clinic processes were required (Table 3)

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"We have a fair uptake of home therapies because of our unique geography; people live far away from the clinic and would prefer to get treatment at home. The challenge is to provide ongoing support to these people in rural/remote communities. By limiting referral to the CKD clinic (eGFR of 30) we are missing out on opportunities for prevention. CKD programs could be expanded to provide prevention or increased opportunity for slowing progression of disease".

#### Strengths noted in renal programs

Several points were also noted with respect to what worked well in the renal programs in the care of patients with kidney disease (Table 4).

#### **Future directions**

Establishing current practice across Canada is important, though a further important step will be to assess which models of care, or specific components of care, are associated with the best care and outcomes for people with CKD.

This survey, and the list of contacts generated herein will facilitate the development of a national network of CKD clinics. Such a network could use the results from this survey, as well as information on local practice to prioritize knowledge translation activities that the CANN-NET Knowledge User and Knowledge Translation Committees can pursue, particularly around the timing of dialysis initiation and dialysis modality choices. Furthermore, the network may facilitate the conduct of clinical trials to test novel interventions or strategies within the context of those models of care.