

Project 3 – Identify and Promote Shared Clinical Tools for Kidney, Heart Disease and Diabetes Health Professionals: Environmental Scan

Draft for Discussion

Scope: This environmental scan identifies existing clinical tools that could be shared by kidney, heart disease and diabetes health professionals. The results of the scan will be presented according to a structure based on the British Columbia Service Framework Approach to health system improvement.

Defining C-K-D: Substantial evidence indicates that patients who develop chronic kidney disease, diabetes or cardiovascular diseases are at significantly higher risk than the general population for one of the other chronic diseases (*Please see Appendix A for statistical data*). The evidence suggests that these diseases are related. The British Columbia C-K-D initiative aims to strategically and effectively prevent, diagnose, treat and manage these chronic diseases through innovative collaborative approaches.

Clinical Tool Categories: Clinical tools support health care professionals in a broad spectrum of tasks. This environmental scan divides clinical tools into two general categories:

1. *IT-Enabled Clinical Tools:* The major emphasis in this section is on electronic patient registries.
2. *Non-IT Dependent Clinical Tools:* The major emphasis in this section is on clinical guidelines for treatment and flowcharts. *It should be noted that these tools could be distributed and managed via the internet, but the internet is not a necessary component for successful adoption.* These clinical tools provide health care professionals with information pertinent to the multiple tasks they must undertake to successfully work with chronic disease patients, including:
 - *Continuing Professional Education (CPE)*
 - *Strategies for communicating with patients*
 - *Links to chronic disease specialists and organizations*
 - *Provision of flowcharts, forms and other tools to ensure successful continuity of care*

Major International Clinical Tool Examples

IT-Enabled Clinical Tools - *International Chronic Disease Registries:*

Australia: the National Primary Care Collaborative has launched diabetes and chronic heart disease registries (<http://www.npcc.com.au/collectingmeasures.html>). These

registries detail the number of patients with diabetes and chronic heart disease, the stages of the disease, and what treatments the patients are taking to manage the disease. Kidney disease data is collected by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), which is funded by the federal governments of both departments (<http://www.anzdata.org.au/>).

United Kingdom: The NHS began operating the Central Cardiac Audit Database in 1996 (http://www.icservices.nhs.uk/ncasp/pages/audit_topics/CHD/CCAD-old.asp) and the National Diabetes Audit in 2004 (http://www.icservices.nhs.uk/ncasp/pages/audit_topics/diabetes/about-new.asp). These two programs are components of the NHS's National Clinic Audit Support Programme (NCASP). It should be noted that kidney disease data is not a current focus of the NCASP.

Kidney disease data is collected via the UK Renal Registry, which collects data quarterly via automatic downloading from renal unit databases. The Registry has been publishing reports annually since 1998, “to allow comparative audit of facilities, patient demographics, quality of care and outcome measures (http://www.renalreg.com/About_Frames.htm). Coverage is still an issue in Britain, with only 85% of renal units reporting. 100% of those in Wales and Scotland report. Scottish data, however, is collected via the Scottish Renal Registry, a separate database. Nevertheless, “statistical data from the Scottish Renal Registry is incorporated into Renal Renal Registry reports” (<http://www.renal.org/Registries/registries.html>).¹

United States: The United States Renal Data System (USRDS), first started in 1988, “is a national data system that collects, analyzes, and distributes information about end-stage renal disease (ESRD) in the United States” (<http://www.usrds.org/>). USRDS is partially funded through federal bodies such as the National Institutes for Health and the Centers for Medicare and Medicaid. It should be noted that data collected via the USRDS recognizes the “important interaction of age, diabetes, and comorbid cardiovascular disease on survival” of patients with kidney disease (USRDS, 2004, p 174). In 2005, the USRDS report included a cardiovascular supplemental. This indicates a trend towards broadening the data collection mandate to include multiple chronic diseases.

There is little evidence of current collaborative database/registry approaches. Further, there is a clear divide between the kidney disease community and the heart and diabetes communities. Bodies that collect data for kidney disease are funded and structured independently. Heart disease and diabetes registries, while still separate, tend to be funded and organized within the same structure.

Non-IT Dependent Clinical Tools - Guidelines:

¹ To access the annual Renal Registry reports, please see: http://www.renalreg.com/Downloads_Frame.htm.

There are countless international examples of medical guidelines and best practices.² For the sake of brevity, this environmental scan shall focus on the UK experience with C-K-D guidelines.

In the UK, the NHS works closely with the National Institute for Health and Clinical Excellence (NICE), which describes itself as an “independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health” in England and Wales (<http://www.nice.org.uk/page.aspx?o=home>). NICE has published an array of guidelines on a range of diseases.³ Similarly, the Scottish Intercollegiate Guidelines Network (SIGN) publishes a comprehensive series of guidelines, including ones for the management of diabetes and a series of guidelines related to heart disease.⁴

In 2005, the Renal Association published guidelines for the management of CKD. While a concise 18 page summary of the guideline was published, the full guideline runs to 116 pages (<http://www.renal.org/CKDguide/ckd.html>).⁵ The guideline was created in association with multiple stakeholders, including the NHS, and draws on existing NICE guidelines for diseases related to chronic kidney disease (<http://www.renal.org/CKDguide/full/Intro.htm>). It isn't clear, however, why NICE was not charged with the task of creating the guideline.

This evidence suggests that a division between the CKD community and the heart disease and diabetes communities exists. This same division was also evident in the environmental scan of international registries in the international arena.

Major British Columbia Clinical Tool Examples

IT-Enabled Clinical Tools - *Chronic Disease Registries:*

BC has developed a number of patient registries for diabetes, CKD and heart disease. Other registries are in development for chronic diseases such as depression and asthma (BC Health Services, 2002, p 4).

PROMIS: The BC Provincial Renal Agency maintains the Patient Record and Outcome Management Information System (PROMIS), “a unique database used to capture information on all BC patients known to nephrology teams. It provides the only information tool linking hospitals providing direct renal patient care, the University of BC (UBC), research organizations, financial groups and other organizations. PROMIS also enables improvements in clinical care, provides caregivers access to indicators of care, and supports research into both disease processes and evaluation of various

² See, for example, the World Health Organization's list of notable guidelines:

http://www.who.int/chronic_conditions/implementation/tools/providers/en/index.html

³ To access the NICE guidelines, please see: <http://www.nice.org.uk/page.aspx?o=cat.diseaseareas>

⁴ To read SIGN's CHD guidelines, please see <http://www.sign.ac.uk/guidelines/published/#CHD>

⁵ To read the guideline, please see: <http://www.renal.org/CKDguide/full/UKCKDfull.pdf>

treatment strategies” (BC Renal Agency, 2004, p 3-4). Currently, PROMIS collects data from over 30 renal units throughout BC (<http://www.bcrenalagency.ca/HelathPro/PROMIS/>).

British Columbia Diabetes Registry: The National Diabetes Surveillance Strategy’s registry has been in development since 1996. The strategy’s first goal is to “implement a standardized model for the surveillance of certain ‘core’ data. This will yield comparable information on the incidence and prevalence of diabetes, mortality, diabetes -associated diseases, and health-care utilization rates for Canadians with and without diabetes” (<http://www.phac-aspc.gc.ca/ccdpc-cpcmc/diabetes-diabete/english/ndss/index.html>).

The BC diabetes register includes those patients who meet the following criteria, which is largely similar to that developed by the National Diabetes Surveillance Strategy:

- *one or more hospital admissions where diabetes was given as a diagnosis; or*
- *two or more physician services within a year where diabetes was given as a diagnosis; or*
- *one or more PharmaCare claims for insulin, oral hypoglycaemics or glucose testing strips (BC Ministry of Health, 2005, <http://www.healthservices.gov.bc.ca/cdm/practitioners/diabetesreg.html>).*

British Columbia Cardiac Registry: The BC MOH has maintained a cardiac patient registry, which has recorded provincial data on open heart surgeries since 1991 and province-wide data on pacemakers and angio since 1994 (http://www.phac-aspc.gc.ca/ccdpc-cpcmc/cvd-mcv/ccdb/cvd37_e.html).

The Public Health Agency of Canada’s Inventory of Canadian Cardiovascular Disease Databases identifies certain weaknesses with the BC Cardiac Registry. It found that there were “no current consent agreements to follow up with patients for follow up information. [And that there was a] lack of information on post hospital outcomes and quality of life issues” (http://www.phac-aspc.gc.ca/ccdpc-cpcmc/cvd-mcv/ccdb/cvd37_e.html). Further, Volk et al., found that the database had a 9.9% inconsistency rate when database entries were compared with hospital charts, which they attributed to differences in consistencies between certain fields, field types and surgeons (1997, p 907).

BC CDM Toolkit for Practitioners: White has argued that the PHSA must “minimize data re-entry and combine databases and search strategies” in order to optimize registry use and efficiency (2004). A combined registry could be realized via the efforts of the Ministry of Health’s web-based toolkit for BC physicians.

With the support of a grant from Health Canada’s Primary Health Care Transition Fund, the MOH created a web-based toolkit in 2003(BC Health Services, 2003, p 7). This toolkit allows physicians to:

- *Electronically access BC Clinical Practice Guidelines and Protocols developed by the MSP/BCMA Guidelines and Protocols Advisory Committee*

- *Electronically complete patient flow sheets*
- *Automatically generate the following clinical and administrative reports, based on patient flow sheet data:*
 - *Patient Profile Reports that compile all of a patient's chronic care information into a single record that can be printed and maintained in the patient's chart. Aggregation of information on different chronic diseases enables easy access to patient co-morbidity information, and eliminates double entry of patient information.*
 - *Practice Profiles that provide age/gender information on patients with specific chronic diseases for a given practice.*
 - *Recall Reports that list the practice's patients who should be scheduled for their next office visit. These reports also specify required tests or procedures, according to evidence-based BC clinical practice Guidelines and Protocols.*
 - *Run Charts that graph changes in the practice's clinical processes and patient health outcomes over a period of time.*
 - *Patient Education Records that give patients valuable information on their chronic disease, along with a graph of their progress over time on health indicators (e.g., A1C levels; blood pressure).*
 - *Data Extremes Reports that enable the practitioner to identify patients who fall below the practice average on disease-relevant clinical process and health outcome measures.*
- *To coordinate care, share patient flow sheets with the group practice, practice network or specialists via secure Internet data transfer (BC Ministry of Health, 2005).*

The toolkit also links doctors to provincial registries and is able to import and securely store patient electronic health records (Gray, 2004; Chartcare, 2004, p 1). The MOH encourages family physicians to access and use existing provincial registry data to develop their own practice registries (BC Health Services, 2003, p 5-6).

Non-IT Dependent Clinical Tools

Guidelines: In 2004, BC Health Services has published a guideline for the identification, evaluation and management of CKD (Craven, 2005).⁶ The BC guidelines for clinical management of diabetes patients includes a flow sheet that combines guidelines, indicated tests and a timeline to ensure continuity of care (http://www.hlth.gov.bc.ca/msp/protoguides/gps/diabetes_care.pdf). This flow sheet can be printed and inserted in a patient's chart. It would be possible to create a combined flow sheet that includes follow-up tests and guidelines for diabetes *and* kidney and heart diseases.

Another example of a simple tool to ensure continuity of care and patient follow-up that has been implemented in the province is the Vancouver Island Kidney Care Initiative recommendation that doctors "use bright-colored stickers to mark charts of at-risk patients. Each time the office staff and the physician pick up one of the stickered charts,

⁶ To read the guideline, please see: <http://www.healthservices.gov.bc.ca/msp/protoguides/gps/ckd.pdf>.

they are reminded of the risk factors for that patient and the fact that the patient requires ongoing monitoring” (Craven, 2005). Further, colour coded sticker systems are generic enough that they could easily be modified to become a shared tool for monitoring multiple chronic conditions in a single patient.

Flow sheets and coloured stickers may seem deceptively simple. However, they are simply alternate versions of tools that are provided by the online CDM toolkit. These tools are ideal for those practices which do not have internet and computer resources and are thus worth considering as an alternative to the IT options.

It should be noted, however, that *guideline fatigue* may become an issue. Ganz notes, “at the time the guidelines for chronic kidney disease were published, the GPAC had already produced 50 guidelines. The CMA database of guidelines includes 363 guidelines, and the US National Guideline Clearinghouse includes information on 1306 guidelines for physicians” (2005).

Four Standards of Care for C-K-D & Patient Self Management: British Columbia is pursuing a service framework approach to health (*Please see Appendix B*). Thus, it behooves the C-K-D initiative to consider how the promotion of shared clinical tools can be understood through the lens of the four standards of care in the service framework approach.

1. **C-K-D prevention (Staying Healthy):** This standard should be understood as applying to clinical tools that aid doctors in educating their patients about prevention and monitoring their patients for potential problems that could lead to development of one of the C-K-D diseases.
 - *Individual: No role identified at present*
 - *Care provider: Physicians should use guidelines as a CPE tool, enabling them to develop expertise in C-K-D prevention issues, such as the identification of at-risk patients*
 - *Support System: No role identified at present*
 - *Health Care Environment: Pursue collaborative tools agenda as opposed to continuing to offer disease-specific clinical tools*

2. **Early diagnosis of C-K-D (Getting Better)** This standard should be understood as applying to clinical tools that aid in the early diagnosis of any or all of the C-K-D diseases.
 - *Individual: No role identified at present*
 - *Care Provider: Should be knowledgeable of early-warning signs of the diseases and should use flowcharts, guidelines and other tools to begin monitoring those patients who have just developed one of the diseases*
 - *Care Provider: Should report all new disease incidents to registries to aid the research community*
 - *Support System: No role identified at present*

- *Health Care Environment: Provide funding for universal health professional access to electronic registries*

3. Management of C-K-D (Living with Illness) This standard should be understood as applying to clinical tools that aid in the monitoring of chronic disease patients.

- *Individual: No role identified at present*
- *Care Provider: Continue monitoring patient via flow charts, guidelines and other clinical tools*
- *Care Provider: Update electronic registry fields regularly*
- *Support System: No role identified at present*
- *Health Care Environment: Provide funding for universal health professional access to electronic registries*

4. Supporting end stage C-K-D (Coping with End of Life) This standard should be understood as applying to clinical tools that aid doctors in management of the physical and emotional problems that manifest in the end-stages of the diseases.

- *Individual: No role identified at present*
- *Care Provider: Patient-communication guidelines are crucial CPE tools to aid health professionals in dealing with this delicate subject*
- *Care Provider: Enter patient morbidity data into electronic registries*
- *Support System: Could provide input on patient-communication strategies from patient and family perspective*
- *Health Care Environment: Provide funding for universal health professional access to electronic registries*

Service Framework Discussion Points:

- Is *guideline fatigue* a major issue? If so, how can it be overcome without abandoning guidelines? CPE courses might be an option.
- Registries are key components of stages #2-4 of the service framework. If a collaborative C-K-D registry is pursued, should this be at the federal or provincial level?
- IT is a major issue at all levels of the service framework, however it is especially relevant to stages #2-4 as electronic registry data must be entered by health care centres.
- IT is not absolutely necessary for clinical tools such as guidelines and flow charts. Although internet distribution and web-based forms may be more convenient, they are not the only path. As lack of IT funding is often used as an excuse for lack of innovation, would it be worth considering a collaborative approach to a *paper* clinical tool as opposed to an IT-enabled clinical tool?

Appendix A

Canada

Disease	Statistic	Source
Diabetes	Diabetes is a contributing factor in the deaths of approximately 41,500 Canadians each year. Canadian adults with diabetes are twice as likely to die prematurely, compared to persons without diabetes.	Health Quality Council. <i>Chronic Disease Management</i> . 2004: http://www.hqc.sk.ca/portal.jsp?V6ADFD0NmPRD+4vt8vmeKjBIzBf0QfLQkUwK4QBZaJvwO9ghh5dfuYzOVcA+lmY4#Improving_patient_care
	Approximately 2 million Canadians have diabetes. The rate is three to five times higher among Aboriginal people.	Public Health Agency of Canada. <i>Diabetes</i> . 2005: http://www.phac-aspc.gc.ca/ccdpc-cpcmc/diabetes-diabete/english/index.html
	41,483 adult Canadians with diabetes died in 1999/2000.	Health Canada. <i>Responding to the Challenge of Diabetes in Canada: First Report of the National Diabetes Surveillance System (NDSS) 2003</i> . 2003: II.
Cardiovascular Diseases	In 1999, Cardiovascular Diseases were responsible for 36% of all deaths in Canada, making it the leading cause of death in the country.	Public Health Agency of Canada. <i>Cardiovascular Disease Surveillance Online</i> . 2005: http://dsol-smed.phac-aspc.gc.ca/dsol-smed/cgi-bin/cvdchart2?AREA=00&YEAR=99&SEX=3&CCAUSECORE1=View+Chart&AGE=0&DATA_TYPE=A_PIE&PIE_CAUSE=008%3B002%3B003%3B009%3B018%3B109&PIE_ALL=001
	Cardiovascular diseases are the underlying cause of death for 1 in 3 Canadians.	Heart and Stroke Foundation of Canada. <i>The Growing Burden of Heart Disease and Stroke in Canada 2003</i> . 2003: 9.
Kidney Diseases	Recent estimates suggest that as many as 1.9 million Canadians have CKD – most are unaware of it.	The Kidney Foundation of Canada. <i>Kidney Disease: Am I at Risk?</i> 2004: 5
C-K-D Relationship Data	Approximately 80% of people with diabetes will die as a result of heart disease or stroke.	Health Quality Council. <i>Chronic Disease Management</i> . 2004: http://www.hqc.sk.ca/portal.jsp?V6ADFD0NmPRD+4vt8vmeKjBIzBf0QfLQkUwK4QBZaJvwO9ghh5dfuYzOVcA+lmY4#Improving_patient_care
	As many as 30% of people with diabetes also suffer from kidney disease.	BC Renal Agency. <i>Working Together for Better Kidney Health</i> . 2005: http://www.bcrenalagency.ca

	<p>Chronic conditions are the major cause of illness, disability and death in Canada. In 1997, there were a total of 215,669 deaths in Canada with more than 75 per cent of the deaths attributable to one of the following five chronic diseases: cancer, cardiovascular disease, diabetes, kidney disease and respiratory disease.</p>	<p>Province of Manitoba. <i>News [sic] Diabetes and Chronic Disease Prevention Initiative Announced</i>. 2004: http://www.gov.mb.ca/chc/press/top/2004/12/2004-12-07-03.html</p>
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British Columbia

Disease	Statistic	Source
Diabetes	Provincial disease prevalence and incidence rates indicate a diabetes epidemic. Currently, 196,467 British Columbians have been diagnosed with diabetes, and this number is expected to increase 90% by 2010.	BC Health Services. <i>Chronic Disease Management: Update 2003, Year One in Review</i> . 2003: http://www.healthservices.gov.bc.ca/cdm/research/update2003.pdf
Cardiovascular Diseases	According to Health Canada's <i>Cardiovascular Disease Surveillance Online</i> program, 10,154 British Columbians died of cardiovascular diseases in 1999.	Public Health Agency of Canada. <i>Cardiovascular Disease Surveillance Online</i> . 2005: http://dsol-smed.phac-aspc.gc.ca/dsol-smed/cgi-bin/cvdchart2?DATA_SET=MORT&DATA_TYPE=D&YEAR1=99&CAUSE1=008&AGE1=0&SEX1=3&CPROV1=View+Chart
Kidney Diseases	An estimated 145,000 British Columbians may suffer from kidney disease.	BC Renal Agency. <i>Working Together for Better Kidney Health</i> . 2005: http://www.bcrenalagency.ca
C-K-D Relationship	Business cases provided compelling evidence that improved diabetes and congestive heart failure management could save BC's health system approximately \$34 million and \$25 million, respectively, in three years.	BC Health Services. <i>Chronic Disease Management: Update 2003, Year One in Review</i> . 2003: http://www.healthservices.gov.bc.ca/cdm/research/update2003.pdf

Relationship between Diabetes, Cardiovascular Disease and Kidney Disease: A Selection of Statistics from Recent Medical Journal Articles

Statistic	Source
Populations with certain chronic metabolic disorders (eg, diabetes and chronic renal failure) are at substantially increased risk of cardiovascular disease (CVD). Compared with the general population, few epidemiological studies of the determinants of CVD have been done in these groups. This situation is unfortunate, because the absolute risks of myocardial infarction, stroke, and congestive heart failure among some such individuals may be high, so the absolute benefits of effective treatments could also be large.	Baigent C; Burbury K; Wheeler D. Premature cardiovascular disease in chronic renal failure. <i>Lancet</i> . 2000 Jul 8; 356(9224):147.
It remains unclear how much of the association between kidney and vascular disease results from (1) vascular disease causing kidney disease, (2) kidney disease causing vascular disease, or (3) common underlying factors promoting the progression of both.	Curtis B; Parfey P. Congestive Heart Failure in Chronic Kidney Disease: Disease-specific Mechanisms of Systolic and Diastolic Heart Failure and Management. <i>Cardiology Clinics</i> . 2005, 23: 278.
Cardiac mortality for dialysis patients younger than 45 years is more than 100 times greater than in the general population of the United States.	Baigent C; Burbury K; Wheeler D. Premature cardiovascular disease in chronic renal failure. <i>Lancet</i> . 2000 Jul 8; 356(9224):147.
The United Kingdom Prospective Diabetes Study found that almost 40% of patients starting dialysis have diabetes.	Levin A; Stevens L; McCullough P. Cardiovascular disease and the kidney: Tracking a killer in chronic kidney disease. <i>Postgraduate Medicine Online</i> . 2002 April; 111(4): http://www.postgradmed.com/issues/2002/04_02/levin.htm .
Almost half of those Americans who were receiving renal replacement therapy in 1999 had a primary diagnosis of diabetes mellitus, particularly type 2, and more than one quarter a primary diagnosis of hypertension.	Brown WW; Collins A; Chen SC; King K; Molony D; Gannon MR; Politoski G; Keane WF. Identification of persons at high risk for kidney disease via targeted screening: the NKF Kidney Early Evaluation Program. <i>Kidney International. Supplement</i> . 2003 Feb; (83):S50.
Cardiovascular disease is the leading cause of death in dialysis patients, accounting for almost half the deaths in this population.	St Peter WL; Schoolwerth AC; McGowan T; McClellan WM. Chronic kidney disease: issues and establishing

	programs and clinics for improved patient outcomes. <i>American Journal of Kidney Diseases</i> . 2003 May; 41(5):903.
Even after stratification by age, gender, race, and the presence or absence of diabetes, cardiovascular mortality in dialysis patients is 10 to 20 times higher than in the general population.	Foley RN; Parfrey PS; Sarnak MJ. Epidemiology of cardiovascular disease in chronic renal disease. <i>Journal of the American Society of Nephrology</i> . 1998 Dec 9; (12 Suppl):S16.

Appendix B

Service Framework Planning Matrix

Levels of Health	Levels of Health Status			
	Staying Healthy	Getting Better	Living with Illness	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

As Presented in: *A Guide to the Development of Service Frameworks in British Columbia*. September 20, 2005: 7.

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