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PRACTICE GUIDELINE

# Hereditary colorectal cancer registries in Canada: report from the Colorectal Cancer Association of Canada consensus meeting; Montreal, Quebec; October 28, 2011

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## ABSTRACT

At a consensus meeting held in Montreal, October 28, 2011, a multidisciplinary group of Canadian experts in the fields of genetics, gastroenterology, surgery, oncology, pathology, and health care services participated in presentation and discussion sessions for the purpose of developing consensus statements pertaining to the development and maintenance of hereditary colorectal cancer registries in Canada. Five statements were approved by all participants.

## KEY WORDS

Colorectal cancer, cancer registry, Lynch syndrome, familial adenomatous polyposis, *MUTYH*-associated polyposis, hereditary cancer, colorectal cancer screening, Canada

## 1. TERMS OF REFERENCE

The purpose of the Colorectal Cancer Association of Canada consensus meeting held October 28, 2011, was to develop a set of consensus statements about the importance of developing and maintaining hereditary colorectal cancer registries (HCRCRS) in Canada. A representative group of experts from across Canada, drawn from key disciplines in genetics, gastroenterology, surgery, oncology, pathology, and health care services, participated in the meeting (Table I). The present report summarizes information on HCRCRS for health care providers involved in clinical care of individuals with colorectal cancer (CRC), for decision-makers responsible for funding programs in cancer control and advanced clinical care, and for provincial CRC screening programs. The target audience includes stakeholders (provincial government cancer agencies, hospitals, and relevant non-governmental cancer organizations) responsible for prevention, service delivery, and funding decisions related to the management of patients and family members at high risk for CRC. The recommendations provided here are based on presentations and discussions of the best available evidence.

## 2. BACKGROUND

Since the establishment of the St. Mark's Hospital Polyposis Registry in London, England in 1924[1], numerous successful high-risk CRC and polyposis registries have been developed worldwide. In Canada, there are currently three well-established HCRCRS: the clinic-based Familial Gastrointestinal Cancer Registry[2] at Mount Sinai Hospital in Toronto, Ontario, supported by the Zane Cohen Centre for Digestive Diseases, and two research-based registries, the Ontario Familial Colorectal Cancer Registry[3] (part of the international Colon Cancer Family Registries funded by the National Institutes of Health in the United States) based in Toronto, Ontario, and the Newfoundland Colorectal Cancer Registry[4] at Memorial University in St. John's, Newfoundland and Labrador, which was funded by the Canadian Institutes of Health Research (grant numbers CRT-43821 and FRN-79845) and by the National Cancer Institute of Canada (grant numbers 18223 and 18226 until 2010). More recently, in 2011, The Ride to Conquer Cancer at the Jewish General Hospital has provided funding to help implement a HCRCR in Montreal, Quebec.

Hereditary CRC registries are typically multidisciplinary, offering genetic counselling and testing, colonic and extracolonic cancer screening, psychosocial services, patient and physician education, and research opportunities. Although the primary function may vary from centre to centre, the consensus group agreed on 11 roles that a HCRCR should play (Table II), including identification of

TABLE I Participants in the Colorectal Cancer Association of Canada consensus meeting; Montreal, Quebec; October 28, 2011

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| *Steering committee* | |
| Bernard Candas | Researcher, Institut national de santé publique du Quebec, Laval University, Quebec City, QC |
| Blaise Clarke | Pathologist, University Health Network, Toronto, ON |
| William Foulkes | Cancer Geneticist, McGill University, Montreal, QC |
| Robert Gryfe | Colorectal Surgeon, Mount Sinai Hospital, Toronto, ON |
| Spring Holter | Genetic Counsellor, Mount Sinai Hospital, Toronto, ON |
| Michael Woods | Molecular Geneticist, Memorial University, St. John's, NL |
| *Host* | |
| Barry Stein | President, Colorectal Cancer Association of Canada |
| *Meeting facilitator* | |
| Heidi Rothenmund | Genetic Counsellor, Jewish General Hospital, Montreal, QC |
| *Participants* | |
| Peter Ainsworth | Molecular Geneticist, London Health Sciences Centre, London, ON |
| Linlea Armstrong | Clinical Geneticist, BC Cancer Agency, Vancouver, BC |
| Melyssa Aronson | Genetic Counsellor, Mount Sinai Hospital, Toronto, ON |
| Alan Barkun | Gastroenterologist, McGill University Health Centre, Montreal, QC |
| Jodi Campbell | Genetic Counsellor, Credit Valley Hospital, Mississauga, ON |
| Bernie Chodirker | Medical Geneticist, Health Sciences Centre, Winnipeg, MB |
| George Chong | Molecular Geneticist, Jewish General Hospital, Montreal, QC |
| Zane Cohen | Colorectal Surgeon, Mount Sinai Hospital, Toronto, ON |
| Elizabeth Dicks | Clinical Scientist, Memorial University, St. John's, NL |
| Catherine Dube | Gastroenterologist, University of Calgary, Calgary, AB |
| Cynthia Forster-Gibson | Medical Geneticist, Credit Valley Hospital, Mississauga, ON |
| Dawna Gilchrist | Medical Geneticist, University of Alberta, Edmonton, AB |
| Jane Green | Geneticist, Memorial University, St. John's, NL |
| Andrea Hawrysh | Genetic Counsellor, Kingston General Hospital, Kingston, ON |
| Gilles Jobin | Gastroenterologist, Hôpital Maisonneuve-Rosemont, Montreal, QC |
| Lidia Kasprzak | Genetic Counsellor, McGill University Health Centre, Montreal, QC |
| Edmond Lemire | Medical Geneticist, Royal University Hospital, Saskatoon, SK |
| Lynn Macrae | Genetic Counsellor, Jewish General Hospital, Montreal, QC |
| Chantal Morel | Medical Geneticist, University Health Network, Toronto, ON |
| Laura Palma | Genetic Counsellor, McGill University Health Centre, Montreal, QC |
| Nicole Perrier | Genetic Counsellor, Kingston General Hospital, Kingston, ON |
| Renee Perrier | Medical Geneticist, Alberta Children's Hospital, Calgary, AB |
| Jenna Scott | Genetic Counsellor, BC Cancer Agency, Vancouver, BC |
| Kim Serfas | Genetic Counsellor, Health Sciences Centre, Winnipeg, MB |
| Harminder Singh | Gastroenterologist, University of Manitoba, Winnipeg, MB |
| Alan Spatz | Pathologist, Jewish General Hospital, Montreal, QC |
| Marsha Speevak | Laboratory Geneticist, Credit Valley Hospital, Mississauga, ON |
| Wendi Stoeber | Genetic Counsellor, Royal University Hospital, Saskatoon, SK |
| Laura Sware | Program Manager, BC Cancer Agency, Vancouver, BC |
| Deborah Terespolsky | Medical Geneticist, Credit Valley Hospital, Mississauga, ON |
| Eva Tomiak | Medical Oncologist, Children's Hospital of Eastern Ontario, Ottawa, ON |
| Lea Velsher | Medical Geneticist, North York General Hospital, North York, ON |
| Debrah Wirtzfeld | Surgical Oncologist, Cancercare Manitoba, Winnipeg, MB |
| Nora Wong | Genetic Counsellor, Jewish General Hospital, Montreal, QC |
| Ping Yang | Laboratory Geneticist, Credit Valley Hospital, Mississauga, ON |
| Sonya Zaor | Genetic Counsellor, Jewish General Hospital, Montreal, QC |
| George Zogopoulos | Hepatobiliary Surgeon, McGill University Health Centre, Montreal, QC |

TABLE II Roles of a hereditary colorectal cancer (CRC) registry

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| 1 | Identification of new probands with CRC |
| 2 | Identification of new at-risk relatives |
| 3 | Facilitation or coordination of CRC screening for hereditary CRC families |
| 4 | Facilitation or coordination of extracolonic cancer screening for hereditary CRC families |
| 5 | Periodic family history updates |
| 6 | Education of probands and family members |
| 7 | Education of health care providers about hereditary CRC conditions |
| 8 | Recruitment for research |
| 9 | Collaboration with other hereditary CRC registries |
| 10 | Quality control |
| 11 | Ongoing evaluation of hereditary CRC registry services and their results |

high-risk patients and their at-risk family members; facilitation and coordination of appropriate clinical screening; provision of education to patients, family members, and health care providers; enrolment of patients in relevant research studies; and ongoing evaluation of the HCRCR services and impact. The ultimate goals are prevention and early detection of CRC.

Registry participants with a hereditary predisposition are most often diagnosed with either Lynch syndrome [LS (also known as hereditary non-polyposis colorectal cancer)], or familial adenomatous polyposis (FAP). Both syndromes are well-characterized autosomal dominant conditions associated with a high risk for CRC, young age of diagnosis, and elevated risk for extracolonic cancers[5,6]. A more recently identified syndrome, *MUTYH*-associated polyposis (MAP), is a recessively inherited condition with a high risk for colorectal polyposis and cancer[7]. The foregoing conditions represent the most common of the known hereditary CRC (HCRC) syndromes, with lifetime risks for CRC as high as 80% for LS and approaching 100% for MAP and FAP when left untreated[8]. Three additional groups at high risk for CRC or polyposis include families with familial colorectal cancer type X[9], families with unexplained polyposis[10], and people diagnosed with CRC at very young ages (≤40 years)[11]. Although the genetic causes in each of these groups is unclear, HCRCRs play a large role in the identification and characterization of high-risk families, in gene discovery efforts, and in determining the best available clinical management[9,10,12,13].

The risk for CRC in people with a strong family history is significantly reduced with appropriate cancer screening[14,15]. Well-established evidence-based recommendations are available for CRC screening and surgery for individuals with LS and FAP[5,6], and screening guidelines have been developed for MAP[16]. Despite the high risk for cancer and the preventive benefits of CRC screening in these populations, multiple barriers often prevent patients from undergoing appropriate surveillance. Those barriers can include lack of public awareness, patient misinformation, lack of physician endorsement, uncertainty about who is responsible for managing an augmented screening protocol and contacting at-risk family members, and anticipation of embarrassment or discomfort during screening[17,18]. Other structural barriers include restrictions resulting from privacy and access to information acts, public policies, and access to appropriate services[19–23]. Some of the barriers may be overcome by patient and physician education and multidisciplinary interventions.

Overall, the largest benefits reported by HCRCRs are derived primarily from increased enrolment of at-risk family members who subsequently undergo appropriate cancer screening[24,25]. Although barriers to consistent, long-term surveillance for these high-risk carriers of germline mutations remain, centralized cancer registries have reported impressive rates of screening compliance, with noncompliance rates of less than 5%[26–28]. As a result, registries have demonstrated a decline in the incidence of CRC; improved survival for relatives who are identified to be mutation carriers and who subsequently enrol in appropriate screening; and for newly diagnosed relatives, a life expectancy comparable to that in a general population[15,28–30]. Equally important is the identification of non-carrier relatives who might be undergoing augmented screening unnecessarily.

The direct and immediate clinical impact of establishing new registries is exemplified by the experience of the HCRCR at the Jewish General Hospital in Montreal, Quebec. Within the first few months of recruitment, 54 high-risk individuals were recruited for clinical or research purposes, including 19 at-risk relatives from 5 mutation-positive families who have since chosen to undergo predictive genetic testing. Thus far, 1 *in situ* CRC was identified in a known LS carrier who had not been undergoing screening before registry enrolment; a high-grade dysplastic polyp showing immunohistochemical deficiency consistent with LS was removed from 1 LS carrier who was having difficulties obtaining appropriate screening before enrolment; 3 relatives were found to be non-carriers and were advised to discontinue unnecessary colonoscopic screening; and 2 carriers who had been offered predictive genetic testing by the registry were referred for appropriate cancer screening for the first time.

Other Canadian registries have recruited a significant number of patients and family members with HCRC, many of whom may not have been identified otherwise. Phase 1 of the Ontario Familial Colorectal Cancer Registry identified 46 CRC patients who were confirmed to have LS. As a matter of concern, 40 of those LS patients (87%) met the Ontario Ministry of Health and Long-Term Care criteria for genetic testing, but only 12 (30%) had been appropriately referred for genetic evaluation by their treating physician before study recruitment.

Although most of the work accomplished by the Canadian registries has been carried out as research, much of their experience can be translated to clinical care. For example, based on the experience of the Newfoundland Colorectal Cancer Registry, multiple strategic steps were identified to positively affect the health of individuals in Newfoundland and Labrador who are affected with HCRC:

- Development of appropriate standards for clinical practice and for engagement with patients, families, communities, and the health care system
- Creation of standardized protocols to ensure continued ascertainment and screening of high-risk individuals with appropriate management
- Application of discoveries in molecular genetics to individuals and families in the population
- Ascertainment of cases representative of the population to identify new genes and mutations causing disease

The Newfoundland Familial Community Cancer Screening Program was subsequently established and opened in August 2010. Operated initially with federal and provincial funding (from the Atlantic Canada Opportunities Agency and the Government of Newfoundland and Labrador), the program now has a goal to obtain long-term sustained funding from the Newfoundland and Labrador Department of Health and Community Services. Services are currently offered to every person diagnosed with one of the more frequent LS-associated cancers in the province—colorectal, endometrial, or ovarian. Since 2008, every patient diagnosed with one of those cancers has received a letter inviting their attendance at a specialized clinic as part of their routine care. Patients are asked to provide family history details that are then assessed by a genetic counsellor and geneticist. Based on level of risk, these individuals and their families are offered genetic counselling to help them better understand how HCRC might affect their family and what they have to do to reduce risk.

In Manitoba, individuals with suspected HCRC syndromes are evaluated by genetic counsellors or medical geneticists from the Winnipeg Regional Health Authority Program in Genetics and Metabolism. On a routine basis, the program provides evaluation for cancer syndromes such as FAP and MAP. However, testing for LS remains problematic. No funding mechanism has been established for LS genetic testing, and therefore many adults with suspected HCRC are likely not referred to the program. Testing for LS can be offered only for a specific mutation (described in Manitoba) found in individuals of Mennonite ethnicity and for mutations previously identified in other relatives. A new proposal for funding and establishing a HCRCR was recently submitted to the provincial health agency.

The combination of genetic testing and targeted surveillance has been shown to be a cost-effective use of resources. The Familial Gastrointestinal Cancer Registry reported significant savings when a prototype FAP family undergoes predictive genetic testing, with surveillance being tailored accordingly[31]. Internationally, other registries have similarly found that the provision of genetic testing and clinical screening for HCRC mutation carriers is effective, considerably less expensive than no surveillance, and an efficient use of resources[32,33]. Although various strategies can be used to identify patients at risk for HCRC, recent cost analyses have shown that registry practices as described here result in significant benefits for which the costs are acceptable[34,35], particularly when at-risk family members are recruited and managed appropriately[35].

In Canada, outside of the HCRCRs in Ontario and Newfoundland and Labrador, it is primary care physicians, medical geneticists, oncologists, surgeons, and gastroenterologists who are largely responsible for identifying and managing patients with HCRC. Whether any single physician is able to carry out each of the time-consuming tasks of eliciting and confirming a family history, facilitating appropriate genetic testing, identifying and contacting at-risk family members, and coordinating the required colonic and extracolonic surveillance is questionable[36,37].

Families with HCRC in Canada are likely underserved: only a small proportion are referred to genetic centres nationwide. Despite current structural barriers, the above-described experiences (conducted mostly in a research context) demonstrate that multidisciplinary cutting-edge expertise is available to expand current HCRCRs and to initiate new ones where none is currently available. Such an initiative would benefit Canadians and the health care system alike.

Families from every province should have access to a HCRCR. The establishment and maintenance of HCRCRs in Canada would facilitate the identification of individuals who have the highest risk to develop CRC and who should be undergoing regular augmented colonoscopic and extracolonic screening. As a result, we might expect to see a decline in polyposis-associated and LS-associated CRC, as well as an increase in cancers detected at earlier, more-treatable stages within this high-risk group. To date, funding for the HCRCRs in Canada has been

largely supported by research grants, donations from patients and families, and foundations in support of cancer research. Ideally, HCRCRs would be funded by provincial departments of health.

## 3. CONSENSUS STATEMENTS

***Consensus Statement 1:*** Hereditary colorectal cancer registries will improve the identification of individuals at increased risk for HCRC.

***Consensus Statement 2:*** Hereditary colorectal cancer registries will improve access to appropriate clinical and genetic screening for individuals at increased risk for CRC.

***Consensus Statement 3:*** Improved access to clinical and genetic screening will help to reduce the incidence of CRC and will improve survival rates for at-risk carrier relatives.

***Consensus Statement 4:*** The population of every province should have access to a provincial HCRCR.

***Consensus Statement 5:*** A Canadian network of HCRCRS would facilitate clinical care and collaborative research.

## 4. DISCLAIMER

The views and opinions expressed in this article reflect solely the consensus reached by the experts present at the conference and do not necessarily reflect the current official policy or position of their employers or of the institutions to which they are affiliated.

## 5. ACKNOWLEDGMENTS

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## 6. CONFLICT OF INTEREST DISCLOSURES

Participants disclosed potential conflicts of interest within the preceding two years: JG has acted as a consultant for Novartis.

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