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Hereditary colorectal cancer screening: A 10-year longitudinal cohort study following an educational intervention

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ABSTRACT

Family history (FH) of a first-degree relative with colorectal cancer (CRC) is associated with two to fourfold increased risk, yet screening uptake is suboptimal despite proven mortality reduction. We developed a FH-based CRC Risk Triage/Management tool for family physicians (FPs), and educational booklet for patients with CRC FH. This report describes physician referral and patient screening behavior 5 and 10 years post-educational intervention, and factors associated with screening.

Longitudinal cohort study. FPs/patients in Ontario and Newfoundland, Canada were sent questionnaires at baseline (2005), 5 and 10 years (2015) following tool/booklet receipt. FPs were asked about CRC screening, patients about FH, screening type and timing. "Correct" screening was concordance with tool recommendations.

Results reported for 29/121 (24%) FPs and 98/297 (33%) patients who completed all 3 questionnaires. Over 10 years 2/3 patients received the correct CRC screening test at appropriate timing (baseline 75%, 5-year 62%, 10-year 65%). About half reported their FP recommended CRC screening (5-year 51%, 10-year 63%). Fewer than half the patients correctly assessed their CRC risk (44%, 40%, 41%). Patients were less likely to have correct screening timing if female (RR 0.78; 95% CI 0.61, 0.99; $p = 0.045$). Patients were less likely to have both correct test and timing if moderate/high CRC risk (RR 0.66; 95% CI 0.47, 0.93; $p = 0.017$) and more likely if their physician recommended screening (RR1.69; 95% CI 1.15, 2.49; $p = 0.007$).

Physician discussion of CRC risk and screening can positively impact patient screening behavior. Efforts are particularly needed for women and patients at moderate/high CRC risk.

1. Introduction

Colorectal cancer (CRC) is common worldwide and is the second leading cause of cancer death in Canada and the United States (Bibbins-Domingo et al., 2016; Leddin et al., 2018). CRC screening has been shown to decrease CRC mortality for individuals at average and high risk (Leddin et al., 2018; Aitkin et al., 2010; Hewitson et al., 2008; Schoen et al., 2012). Heredity plays a major role with up to 30% of CRC due to hereditary factors and approximately 5% linked to inherited mutations in known cancer predisposition genes (e.g. Lynch syndrome,

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Familial Adenomatous Polyposis) (Giardeillo et al., 2014; Kanth et al., 2017; Wells and Wise, 2017). First-degree relatives (FDR) of individuals with CRC have a two to fourfold increased CRC risk (Ait Ouakrim et al., 2013; Lowery et al., 2016) which increases with number of affected relatives, earlier age at diagnosis, and features of a hereditary syndrome (Leddin et al., 2018; Lowery et al., 2016).

Screening recommendations for people with a CRC family history (FH) are tailored to risk. For those with a FDR with CRC, particularly under age 60, colonoscopy every 5 years is recommended starting at age 40 or 10 years younger than the youngest CRC diagnosis (Leddin et al., 2018; Lowery et al., 2016; Network and Clinical Practice Guidelines, 2013; Rex et al., 2017). For those with a second-degree relative with CRC diagnosed under age 50, colonoscopy is recommended every 5–10 years from age 50 (Lowery et al., 2016) or fecal immunochemical testing (FIT) has recently been recommended as an alternative, following average risk guidelines (Leddin et al., 2018). Current recommendations for those with Lynch syndrome are colonoscopy every 1–2 years beginning at age 20–25, or 2–5 years before the youngest CRC diagnosis if made before age 25 (Giardeillo et al., 2014; Wells and Wise, 2017; Network and Clinical Practice Guidelines, 2013).

Despite these recommendations, uptake of CRC screening remains suboptimal. A meta-analysis of reported screening rates for people with at least one FDR with CRC showed only 40% had undergone one or more colonoscopies (Ait Ouakrim et al., 2013a). A more recent review showed less than 50% adherence to recommended guidelines for initiation age and screening interval among persons with a CRC FH (Lowery et al., 2016).

To address the issue of suboptimal CRC screening, in 2005 we developed a point-of-care tool for family physicians (FPs), stratifying patient CRC risk and screening recommendations based on FH (Mount Sinai Hospital) and an information booklet for patients with a CRC FH (Mount Sinai Hospital). We evaluated these materials with FPs and their patients in Ontario (ON) and Newfoundland (NL), Canada. Three months following receipt of these materials, questionnaire responses showed a significant increase in FPs' self-reported confidence in CRC risk assessment, and correct screening recommendations for CRC patient vignettes (Carroll et al., 2014). This study reports on participating physician and patient CRC screening practices 5 and 10 years following this educational intervention, and factors associated with appropriate CRC screening.

2. Methods

2.1. Study population

A random sample of FPs in ON (n = 485) and NL (n = 175), provided by the College of Family Physicians of Canada, were invited by mail to participate in the initial phase which involved completing a questionnaire prior to and 3 months after receiving the CRC Risk Triage/Management Tool *(Tool)*. Participating physicians were asked to invite consecutive patients aged 18 or older, with a family member with CRC to participate in the study and were provided with a study summary sheet for this purpose. Recruitment of patients also occurred through posters and brochures in the FP's office, with the assistance of office staff. The brochure included a postage-paid postcard which was a request for more information about the study and was completed with the patient's name and telephone number to enable the study coordinator to contact them. It could be mailed by the receptionist or patient themselves. On receipt of the postcard, the study coordinator would contact the patient, discuss the study in further detail and obtain verbal consent. Participating FPs and patients who gave consent for re-contact, were mailed questionnaires 5 and 10 years post-intervention. A stipend of $300 CAD was provided at the end of the initial phase of the study to compensate FPs for their time in completing study materials. This report describes results for the cohort of FPs and their patients who completed questionnaires at baseline, 5 and 10 years.

2.2. Tools

The *Tool* consisted of a card with four FH stratifications of CRC risk (high or moderate risk for hereditary/familial CRC; low risk for hereditary/familial CRC but still at increased risk of CRC; population CRC risk) (BOX 1. Hereditary Colorectal Cancer CRC Syndromes and Risk Categories) and management recommendations tailored to risk. As we were interested in screening behaviors of those with a CRC FH, patients at population CRC risk were ineligible for this study. Specific recommendations regarding screening test [e.g. colonoscopy or Fecal Occult Blood Test (FOBT)] and frequency, and if referral to a genetics clinic was recommended, were provided (Network and Clinical Practice Guidelines, 2013). The *Tool* was based on the literature, as well as ON and NL guidelines in 2005 (Leddin et al., 2004; Predictive Cancer Genetics Steering Committee, 2001).

The *Family History of Colorectal Cancer* patient booklet contained information about familial and hereditary CRC, guidelines for self-identifying CRC risk based on FH, a description of types of CRC screening tests and recommendations for each risk category (Mount Sinai Hospital). It was designed by a multidisciplinary team, modeled after a similar aid for hereditary breast cancer which was successfully evaluated and implemented (Warner et al., 2003). The booklet was piloted with two patient focus groups and revised based on feedback.

2.3. Study method

Participating FPs completed a baseline questionnaire about their CRC screening practices, knowledge of hereditary CRC, and, for 8 clinical vignettes of varying CRC risk, their risk assessment, recommended screening, and whether they would refer to a genetics clinic. The vignettes were designed to determine FPs' knowledge and ability to assess CRC hereditary risk and recommend appropriate screening, all topics covered in the *Tool*. Following receipt of the completed questionnaire, they were sent the *Tool* and patient information booklet and three months later received a follow-up questionnaire. Those results have been previously reported (Carroll et al., 2014). If FPs gave permission for re-contact, they were mailed a similar questionnaire at 5 (2010) and 10 years (2015). The 2015 questionnaire asked FPs to indicate their risk assessment/management for three of the original vignettes (high, moderate and low risk of hereditary CRC). They were not prompted or prohibited from using the *Tool*.

Participating patients were sent a baseline questionnaire with questions about their FH, CRC screening, CRC concern, and 15 knowledge-related questions about CRC and screening. At 5 and 10 years, they were sent similar questionnaires, asking for FH and CRC screening updates.

2.4. Outcome measures and analysis

The primary outcome measure was the proportion of patients receiving the correct CRC screening test at the appropriate time interval. Two investigators (JC, KS) independently classified each patient's self-reported CRC screening history as correct or incorrect screening test/

BOX 1
Hereditary Colorectal Cancer (CRC) Syndromes and Risk Categories.
Tables

Hereditary Colorectal Cancer Syndromes

HNPCC – Hereditary Non-Polyposis Colorectal Cancer: Most common form of hereditary CRC (approximately 1-2% of all CRC diagnoses). Individuals with HNPCC are at high risk for developing CRC and endometrial cancer. There is also an increased risk for certain other cancers, particularly other gastrointestinal and gynecological cancers. **HNPCC-associated cancers:** colorectal, endometrial, small bowel, ureter, kidney (transitional cell), sebaceous adenoma/carcinoma, ovarian, pancreatic, gastric, primary brain, primary hepatobiliary cancer.

FAP – Familial Adenomatous Polyposis: Very rare condition (<1% of CRC) characterized by 100s to 1000s of colorectal adenomatous polyps beginning as early as puberty. A variant known as attenuated FAP may occur with <100 colorectal adenomatous polyps.

High Risk for Hereditary/Familial CRC	Moderate Risk for Hereditary/Familial CRC	Low Risk for Hereditary/ Familial CRC But Still at Increased Risk of CRC	Population Risk for CRC
☐ Any blood relative of an individual with a known HNPCC or FAP genetic mutation **or** ☐ 3 or more relatives on the same side of the family, at least 1 with CRC and 2 or more with any combination of the above underlined HNPCC-associated cancers • 1 of whom is a 1st degree relative of the other 2 **and** • 1 relative diagnosed < age 50 **and** • at least 2 successive generations (suggestive of HNPCC) **or** ☐ > 10 colorectal adenomatous polyps • Personal history **or** • 1st or 2nd degree relative (suggestive of FAP/attenuated FAP)	Meets none of the high risk criteria and ☐ 1st or 2nd degree relative with CRC ≤ age 35 **or** ☐ 1st or 2nd degree relative with 2 or more of the above underlined HNPCC-associated cancers **or** ☐ 2 or more 1st or 2nd degree relatives on the same side of the family with CRC diagnosed < age 50 **or** ☐ 3 or more relatives with any HNPCC-associated cancers at any age, on same side of the family, at least 1 of whom has CRC	Meets none of high or moderate hereditary/familial risk criteria **and** ☐ 1st degree relative with CRC > age 35 **or** ☐ 2nd degree relative with CRC age 35 – 50 **or** ☐ ≥ 2 2nd degree relatives with CRC > age 50 **or** ☐ 1 1st degree or ≥ 2 2nd degree relatives with colorectal polyps **or** ☐ Personal history of 1 – 10 colorectal adenomatous polyps **or** ☐ Personal history of inflammatory bowel disease	Meets none of the other risk criteria but has 1 in 16 lifetime risk of developing sporadic CRC

time interval based on their reported FH and *Tool* recommendations. Consensus was reached if differences existed. This study assessed under-screening not over-screening. Patient knowledge was determined from answers to 15 CRC questions with a high score defined as ≥8 out of 15. FP ability to correctly evaluate 3 clinical vignettes was scored as 1 point for each correct answer on 5 components: risk assessment, choice of surveillance method, starting age, interval, and referral to a genetics clinic, with a maximum score of 15. Outcome measures were evaluated at baseline, 5 and 10 years.

Changes over time in FP- and patient-reported screening, knowledge, use of tools, and patient risk estimation were assessed using McNemar's and Cochran's Q tests. Repeated measures analysis of variance (ANOVA) evaluated the change in mean score (correct responses) over time for the three clinical vignettes.

Bivariate and multivariate robust Poisson logistic regression models were used to assess predictors of correct test, correct timing, and correct test *and* timing. Robust Poisson models were used to guard against the odds ratios being artificially inflated because of the high prevalence of outcomes (Petersen and Deddens, 2008). Patient covariates used in the models included: sex, province, age ≥ 50, risk level (low vs. moderate/high), correct risk perception, FP discussion of CRC FH, patient concern about risk, and patient knowledge (high vs. low).

Ethics approval was received from the Mount Sinai Hospital Research Ethics Board and the Memorial University Human Investigation Committee.

3. Results

3.1. Response rates and demographics

Of the 660 FPs invited to participate in 2005, 121 (18%) agreed. Of the 353 patients recruited by FPs in 2005, 297 (84%) agreed to participate. Results are reported for 29/121 (24%) FPs and 98/353 (28%) of their eligible patients, who completed questionnaires at baseline, 5 and 10 years (Fig. 1). Baseline demographics are reported in Table 1. There were no significant differences in the demographics of physicians and patients who completed the 10-year questionnaire compared to those who dropped out (Table 1). At the beginning of the study, 302 patients were recruited by 72 physicians, a mean of 4 patients/physician, and range of 1–11. Completing the study after 10 years were 105 patients recruited by 51 physicians, mean of 2 patients/physician and range of 1–6 patients.

3.2. FP screening practices

Almost all FPs reported at all three time points that they routinely asked patients about cancer FH. The vast majority reported recommending FOBT screening for patients aged ≥ 50 who are at population CRC risk, with no significant change over 10 years. Approximately one quarter of FPs reported recommending both colonoscopy and FOBT to patients with a CRC FH and letting patients decide which they preferred, the remainder recommending colonoscopy, with no change over the last 5 years (Table 2).

3.3. Patient reported screening

Over 10 years, approximately 2/3 of patients received both the correct CRC screening test *and* received it at the appropriate time interval. Correct screening interval alone dropped after 2005. Over half reported their FP had recommended screening in the past 5 years; the majority reported discussing CRC FH with their FP (Table 3).

3.4. FP and patient knowledge

Significant increases in mean scores for the FP clinical vignettes were found at 3 months following the intervention (2005) in assessment of patient risk, screening interval, whether to refer to genetics, and total mean score, all of which decreased by 2015 (Table 4). FP self-assessed knowledge of hereditary CRC went from 68.9% good/very good/satisfactory in 2005 to 75.8% in 2015 ($p = 0.75$).

Fewer than half the patients assessed their CRC risk correctly with no significant change over 10 years. Of those who incorrectly assessed their risk, roughly half under-estimated and about 10% over-estimated with no significant change (Table 5). A high score on the patient knowledge questions (≥8/15) significantly increased from 40.2% to 61.5% ($p < 0.001$) over 10 years.

3.5. Predictors of correct test and timing

Significant results from the bivariate Poisson logistic regression analysis are shown in Table 6. Patients who reported at 10 years that their FP recommended screening were significantly more likely to have had the correct screening test, correct timing, and correct screening test at the correct time. Patients at moderate/high risk of CRC based on FH at 5 years were significantly less likely to have had the correct screening test, correct timing and correct screening test at the correct time, and at 10 years less likely to have been tested at the correct time and received the correct screening test at the correct time. At 5 and 10 years, women were significantly less likely to have been screened at the correct frequency. Results from the multivariate analysis indicated that FPs' screening recommendation was a significant predictor of the patient having the correct screening test or being tested at the correct time at 5 (RR 1.43, 95% CI 1.08, 1.90, $p = 0.0128$) and 10 years (RR 2.13, 95% CI 1.45, 3.13, $p < 0.001$). The analysis also showed that, at 10 years, being moderate/high CRC risk based on FH was a significant predictor of the patient not receiving the correct screening test at the correct time (RR 0.64, 95% CI 0.45, 0.90, $p = 0.0097$).

Significantly fewer FPs reported continuing to use the *CRC Tool* 5 to 10 years after the intervention (62.1% to 37.9%, $p = 0.016$) and few patients continued to use the *Booklet* at either time point (11.2% to 10.3%, $p = 1.00$).

4. Discussion

Approximately two-thirds of patients at increased CRC risk due to FH, reported CRC screening that we assessed as being the "correct" test *and* interval. This screening rate did not change significantly over 10 years although the correct screening interval significantly decreased. Variation in screening among relatives of individuals with CRC has been described. A meta-analysis reported that only 31% of subjects with a strong CRC FH had colonoscopy within the recommended 5 year interval (Ait Ouakrim et al., 2013a). A US study showed that adherence to colonoscopy screening among people with a FDR with CRC improved from 25% in 2000 to nearly 66% in 2010, however adherence remained low in those aged 40–49 (38% in 2010) (Tsai et al., 2015). Compliance with colonoscopy guidelines has been reported as higher for those with familial risk (Taylor et al., 2011; Henrikson et al., 2015; Zlot et al., 2012) but in one study did not correlate with degree of risk (Taylor et al., 2011). Reported appropriate screening in our study is at the upper range of these reports, but is still not sufficient. Of particular concern is our finding that those who were at moderate/high CRC risk were significantly less likely to have had correct screening (under-screened) as has been reported by others (Ait Ouakrim et al., 2012).

The extent to which inadequate screening is due to patient or physician factors is unclear. More than half the patients incorrectly self-assessed their CRC risk, with roughly half underestimating. FPs appear to be aware of the importance of FH as almost all report inquiring about it. The majority recommend the "correct" screening test for those at population CRC risk, however a quarter report giving patients with a FDR with CRC the choice of colonoscopy or FOBT, when colonoscopy has generally been advised for these patients (Leddin et al., 2018). Recent recommendations for FIT as an acceptable alternative may

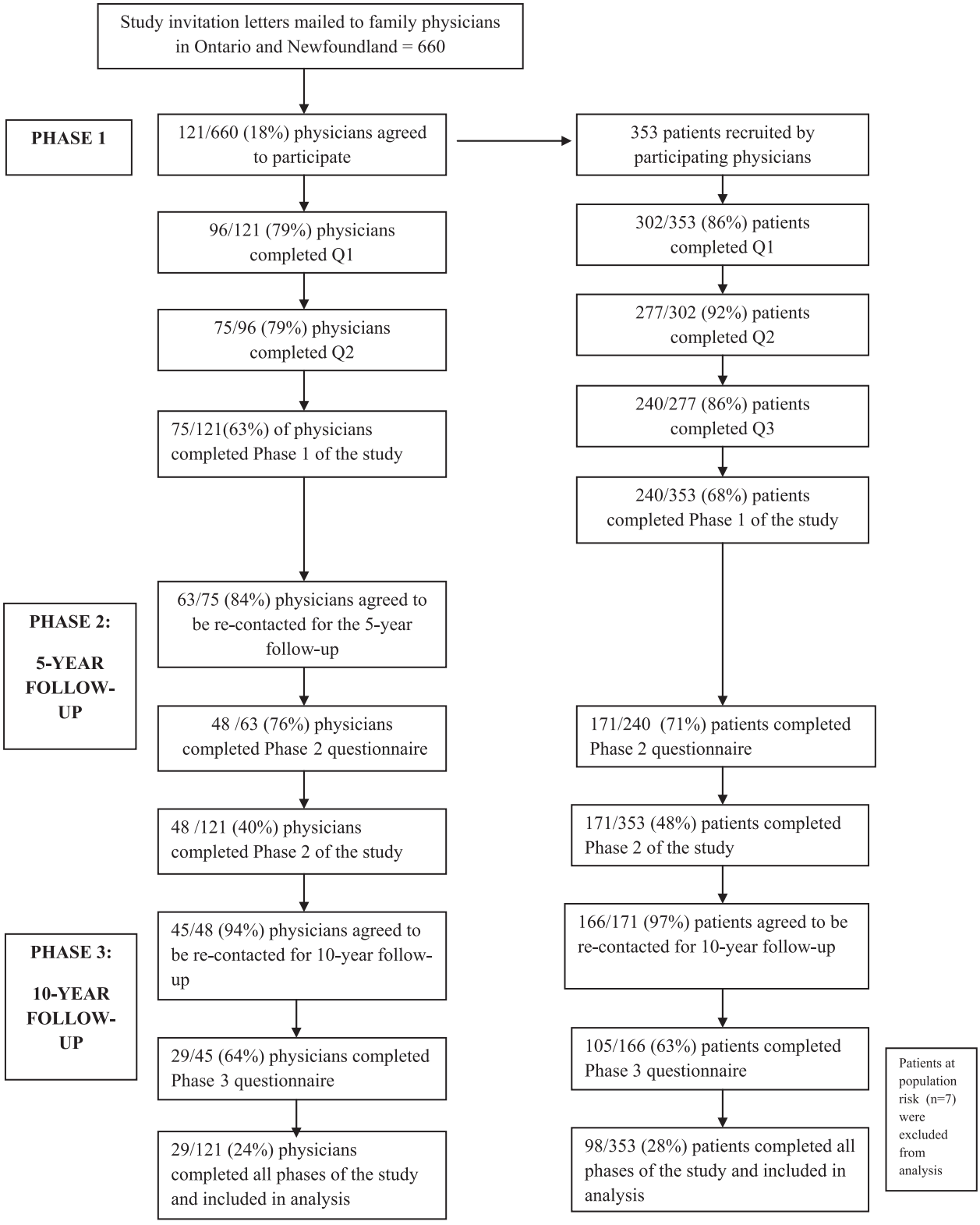

Fig. 1. Recruitment and Response Rates (Canada, 2005–2015).

Table 1
Baseline Demographics of Family Physicians and Patients: Questionnaire Completers (Baseline, 5 and 10 years) and Drop-Outs (Canada, 2005–2015).

	Family Physicians*		Patients*	
	Completers (N = 29)	Drop-Outs (N = 46)	Completers (N = 98)	Drop-Outs (N = 166)
Mean age (SD)	42.3 (9.4) years range: 31–64 yrs	46.1 (9.6) years range: 29–64 yrs	49.6 (11.2) years range: 21–78 yrs	49.7 (13.3) years Range: 16–85 yrs
Mean years in practice (SD)	12.4 (9.5) years range: 1–30 yrs	16.4 (9.5) years range: 0.5–38 yrs	–	–
	# (%)	**# (%)**	**# (%)**	**# (%)**
Female	12 (41.4)	19 (41.3)	74 (75.5)	118 (71.1)
Age ≥ 50 yrs	7 (24.1)	18 (39.1)	49 (50.0)	77 (46.4)
Province				
Ontario	20 (69.0)	31 (67.4)	64 (65.3)	91 (54.8)
Newfoundland	9 (31.0)	15 (32.6)	34 (34.7)	75 (45.2)
Practice location				
Urban	15 (51.7)	25 (54.3)	–	–
Rural	5 (17.2)	17 (37.0)	–	–
Mixed	9 (31.0)	4 (8.7)	–	–
Married	–	–	76 (77.6)	132 (79.5)
Completed high school	–	–	93 (94.9)	152 (91.6)
Patient risk level *(at baseline as assessed by investigators)*				
Low	–	–	65 (66.3)	107 (64.5)
Moderate	–	–	30 (30.6)	51 (30.7)
High	–	–	3 (3.1)	8 (4.8)

* No significant differences were found between study completers and drop-outs

increase screening adherence (Leddin et al., 2018). FP performance on the vignettes indicates a need for education about CRC risk and appropriate screening intervals. Having a physician recommend screening, as in our study, has been found to be one of the most important predictors of screening adherence, increasing the likelihood of screening by 5 to 27-fold (Ait Ouakrim et al., 2013). In our study, only 51% and 63% of patients at 5 and 10 years respectively, reported their FP had recommended screening. It is interesting that almost three-quarters of patients reported having spoken with their providers about their FH of CRC but report that only 51–63% of providers recommended screening. This highlights an opportunity for improved communication for both patients and providers.

It is interesting to hypothesize why women were less likely to have CRC screening at the appropriate time interval (under-screened). An Italian study showed that women's CRC screening adherence was much lower than breast or cervical cancer screening (Bocci et al., 2017). FH of CRC and FP advice were associated with greater adherence to screening colonoscopy (Bocci et al., 2017). Embarrassment was related to decreased colonoscopy compliance with many preferring a female endoscopist (Bocci et al., 2017). They hypothesized that the focus on women's health is more limited to sexual-reproductive health and that women may underestimate their CRC risk.

These findings raise the question of how to improve CRC screening rates particularly for those at moderate/high risk. A Cochrane review showed that providing individuals with a CRC risk score/category resulted in greater uptake of tests (Edwards et al., 2006). Tailored education (personalized information about risk and screening) and face-to-face counselling have been shown to be the most successful means for increasing screening in individuals with a FH of CRC (Lowery et al., 2014; Armelao et al., 2010; Manne et al., 2009; Rawl et al., 2008, 2012; Skinner et al., 2016; Brumbach et al., 2017; Ingrand et al., 2016) although the effect has generally been modest (Carey et al., 2016). A registry with automatic recall of moderate/high risk individuals for screening would enable patients to prompt providers to book screening.

Our findings highlight the importance of a screening recommendation from FPs. Focusing screening on those at moderate/high CRC risk and women with a CRC FH would be most valuable. Lowery found that CRC screening barriers included insufficient FH collection and low knowledge of guidelines by healthcare providers (HCP), as well as poor family communication. Strategies recommended included: improving how HCP collect and use cancer FH, developing clear FH screening guidelines, increasing provider knowledge of CRC risk and screening guidelines, encouraging CRC survivors to contact family members to promote screening and partnering with screening programs to reach high risk groups (Lowery et al., 2016). Our study intervention addressed many of these strategies yet did not increase appropriate screening. Dissemination of educational materials has been shown to have modest benefit in changing physician behavior (Grimshaw et al., 2004). Impact of physician educational interventions has also been shown to decline over time (Carroll et al., 2014; Schroy et al., 2005). A more interactive engagement strategy with FPs and ongoing reminders of a website hosting the *Tool* might have been more successful.

Table 2
Family Physician Self-Reported Behavior, n = 29 (Canada, 2005–2015).

FP Screening Behavior	2005 # (%)	2010 # (%)	2015 # (%)	p-value
Routinely ask patients about FH of cancer (agree/strongly agree)	29/29 (100.0)	29/29 (100.0)	27/28 (96.4)	NS[a]
Routinely recommend FOBT screening for patients age ≥ 50 at population risk for CRC	24/29 (82.8)	28/29 (96.6)	25/28 (89.3)	0.135[a]
When screening patients with FH of CRC: ● Recommends colonoscopy	N/A	18/27 (66.7)	23/29 (79.3)	0.453[b]
When screening patients with FH of CRC: ● Discusses both colonoscopy and FOBT and lets patient decide	N/A	7/27 (25.9)	7/29 (24.1)	1.00[b]

FH - Family History; CRC - colorectal cancer; N/A - not assessed; N/S - not significant.
[a] Cochran's Q test.
[b] McNemar's test.

Table 3
Patient-Reported Screening Behavior, n = 98 (Canada, 2005–2015).

Patient-Reported Screening Behavior	2005 # (%)	2010 # (%)	2015 # (%)	p-value
Received correct[a] CRC screening test	73/98 (74.5)	70/98 (71.4)	73/98 (74.5)	0.838[b]
Received test at appropriate[a] time[c]	83/98 (84.7)	68/98 (69.4)	68/98 (69.4)	0.002[b]
Received correct[a] CRC screening test at appropriate[a] time	73/98 (74.5)	61/98 (62.2)	64/98 (65.3)	0.079[b]
Concern (extreme/moderate) re: CRC risk	50/98 (51.0)	40/98 (40.8)	41/97 (42.3)	0.078[b]
FP recommended screening in past 5 years	N/A	48/94 (51.1)	60/95 (63.2)	0.072[d]
Discussed FH of CRC with FP over past 5 years	89/95 (93.7)	66/89 (74.2)	71/95 (74.7)	0.001[b]

[a] Correct screening determined by concordance with *Tool* recommendations.
[b] Cochran's Q test.
[c] Appropriate time: 2005 = "ever had test"; 2010 = within 5 years; 2015 = within 5 years.
[d] McNemar's test.

Table 4
Family Physician Knowledge: Correct Responses on 3 CRC Clinical Vignettes, n = 29 (Canada, 2005–2015) (Knowledge questions were not included in the 2010 questionnaire).

Clinical Vignette Component	2005 Pre-intervention TIME 1	2005 3 months post-intervention TIME 2	2015 TIME 3	p-value[a]
	Mean Score/3 vignettes (SD)			
1) Patient's Risk:	0.79 (0.77)	2.34 (0.94)	1.03 (0.87)	< 0.001 (F = 16.41)
2) Screening Method:	2.83 (0.38)	2.93 (0.26)	2.93 (0.26)	0.304 (F = 1.20)
3) Starting age for Screening:	2.90 (0.31)	2.90 (0.31)	2.83 (0.38)	0.664 (F = 0.44)
4) Interval for Screening:	0.97 (0.73)	2.21 (0.94)	1.14 (0.83)	< 0.001 (F = 16.47)
5) Referral to Genetics:	1.45 (0.57)	2.52 (0.74)	1.90 (0.77)	< 0.001 (F = 12.78)
Total Score / 15: (5 components in each of 3 vignettes)	8.93 (1.62)	12.90 (2.54)	9.83 (2.12)	< 0.001 (F = 19.25)

[a] Repeated measures ANOVA.

Patients reporting a FDR with CRC are somewhat uncommon in family practice. One review estimated the prevalence of having 1 or more FDRs with CRC to be 3–10% and having 2 or more FDRs with CRC to be about 0.3% (Henrikson et al., 2015). A more recent study in family practice showed one in 14 patients reported at least one FDR with CRC (Plath et al., 2017). FPs have expressed that infrequent experiences with hereditary cancers, including CRC, make risk assessment and appropriate screening challenging (Carroll et al., 2016). For that reason, they have expressed the need for improved electronic medical record (EMR) interfaces to collect FH and provide clinical decision support (Carroll et al., 2014, 2016). Resources are being developed to educate HCP in genetics and hereditary cancer (Jackson et al., 2018; Genetics Education Canada; National Human Genome Research Institute; The Jackson Laboratory; Houwink et al., 2014; Rubanovichet al., 2018). We have developed a website which has current resources on CRC risk and management based on FH as well as other hereditary cancers (Genetics Education Canada).

4.1. Limitations

This study followed a limited number of FPs and their patients with CRC FH, as many dropped out over the years, but its unique strength is following a cohort of patients and their CRC screening over 10 years. A low response rate recruiting FPs from the community, with a significant drop-out rate over time has been shown in other studies (McIsaac et al., 2002). The finding that the demographics of both FPs and patients who completed all 3 questionnaires were no different than drop-outs supports the representativeness of the sample. In addition, we compared demographics of FP responders to those of the Canadian National Physician Survey in 2014 and found the demographics were similar, indicating some representativeness of our sample (The College of Family Physicians of Canada, 2014). Participants were more likely to be interested in CRC which may have increased our reported CRC screening, although there was room for improvement even in this cohort. ON and NL implemented CRC screening programs over the study

Table 5
Patient CRC Risk Estimation, n = 98 (Canada, 2005–2015).

Risk Estimation	2005 # (%)	2010 # (%)	2015 # (%)	p-value[a]
Self-Assessed Level of CRC Risk:				
Low	65/98 (66.3)	59/98 (60.2)	58/98 (59.2)	0.002
Moderate	30/98 (30.6)	32/98 (32.7)	33/98 (33.7)	0.459
High	3/98 (3.1)	7/98 (7.1)	7/98 (7.1)	0.018
Correct CRC Risk Perception	42/96 (43.8)	38/96 (39.6)	40/97 (41.2)	0.814
Under-estimated CRC Risk	41/95 (43.2)	48/96 (50.0)	50/97 (51.5)	0.166
Over-estimated CRC Risk	12/95 (12.6)	10/96 (10.4)	7/97 (7.2)	0.178

[a] Cochran's Q test.

Table 6
Patient Predictors of Patients Having the Correct Screening Test, Correct Timing and the Correct Test at the Correct Time (Canada, 2005–2015).

Patient Covariates	Risk Ratio	95% Confidence Intervals		p-value[a]
		Lower	Upper	
Patient had correct screening test:				
Baseline: Age ≥ 50	1.28	1.01	1.63	0.0418
5 yrs: Patient at moderate to high risk of CRC	0.69	0.51	0.94	0.0174
5 yrs: Patient reported that physician recommended screening	1.44	1.11	1.86	0.0053
10 yrs: Patient reported that physician recommended screening	2.01	1.39	2.91	< 0.001
Patient had test at correct time:				
5 yrs: Female	0.78	0.61	0.99	0.0452
10 yrs: Female	0.78	0.61	0.99	0.0452
5 yrs: Patient at moderate to high risk of CRC	0.72	0.53	0.98	0.0391
10 yrs: Patient at moderate to high risk of CRC	0.69	0.51	0.95	0.0205
10 yrs: Patient reported that physician recommended screening	1.83	1.26	2.68	0.0016
Patient had correct screening test at correct time:				
Baseline: Age ≥ 50	1.28	1.01	1.63	0.0418
5 yrs: Patient at moderate to high risk of CRC	0.68	0.48	0.98	0.0393
10 yrs: Patient at moderate to high risk of CRC	0.66	0.47	0.93	0.0170
10 yrs: Patient reported that physician recommended screening	1.69	1.15	2.49	0.0074

[a] Bivariate robust Poisson logistic regression analysis.

but these were for average risk individuals (Health and Community Services, 2015; Ontario Ministry of Health and Long Term Care, 2015). They may have raised CRC screening awareness, however our screening rates remained stable over 10 years. We were unable to determine whether colonoscopies were screening or diagnostic so cannot comment on over-screening. Lastly, patients may not have accurately reported CRC screening. There is evidence that self-report of CRC screening is fairly accurate, particularly for colonoscopy which is the test most of these patients with a FH of CRC had. Rausher's meta-analysis of the accuracy of self-reported cancer screening history found a mean report-to-record ratio of 2.2 for colorectal endoscopy, suggesting patients in our study may have overestimated screening (Rauscher et al., 2008). Partin similarly showed that over-reporting was a more prevalent source of error. Their sensitivity was 0.97 for colonoscopy with specificity of 0.72 and report-to-record ratio of 1.42 (Partin et al., 2008). Khoja reported that self-reported history of endoscopy within the past 5 years compared with physician report showed dependable agreement with kappa of 0.74 and concordance of 92%, sensitivity of 77% and specificity of 96% (Khoja et al., 2007). Madlensky showed kappa of 0.87 for colonoscopy self-reports compared to medical records (Madlensky et al., 2003). Similar to our study, Khoja used a 5-year reporting interval for colonoscopy and Partin a 10-year interval for studies on accuracy of CRC screening self-report (Partin et al., 2008; Khoja et al., 2007). Finally, we don't have information on how a screening result (e.g. presence or absence of polyps) may have impacted a patient's risk perception, and are therefore unable to indicate how this may have played a role in timing of screening.

5. Conclusions

This study highlights a need for improvement in CRC screening for those at increased risk of CRC due to FH. It suggests that passive educational materials for physicians and patients regarding CRC risk and screening are ineffective. EMR reminders for physicians and a screening recall system for patients would likely be more effective. HCPs who discuss CRC risk and screening with patients individually have a positive impact on patient screening behavior. Women and those at moderate/high CRC risk have a poor CRC screening record and special efforts need to be made to reach out to these groups.

CRediT authorship contribution statement

June C. Carroll: Conceptualization, Methodology, Data curation, Formal analysis, Funding acquisition, Project administration, Resources, Writing - original draft, Writing - review & editing, Supervision. **Joanne A. Permaul:** Conceptualization, Methodology, Data curation, Formal analysis, Investigation, Project administration, Resources, Writing - original draft, Writing - review & editing. **Kara Semotiuk:** Conceptualization, Data curation, Writing - review & editing. **Eric M. Yung:** Conceptualization, Writing - review & editing. **Sean Blaine:** Conceptualization, Writing - review & editing. **Elizabeth Dicks:** Conceptualization, Investigation, Project administration, Resources, Writing - review & editing. **Ellen Warner:** Conceptualization, Writing - review & editing. **Heidi Rothenmund:** Conceptualization, Data curation, Writing - review & editing. **Mary Jane Esplen:** Conceptualization, Writing - review & editing. **Rahim Moineddin:** Conceptualization, Methodology, Data curation, Formal analysis, Writing - review & editing. **John McLaughlin:** Conceptualization, Funding acquisition, Writing - review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Prior presentations

Carroll JC, Semotiuk K, Permaul JA, Yung EM, Blaine S, Dicks E, Warner E, Rothenmund H, Esplen MJ, McLaughlin J. Hereditary Colorectal Cancer Screening: A 10-Year Longitudinal Study Following an Educational Intervention. American Society of Human Genetics. Oct 2017. Poster presentation by J Carroll.

Carroll JC, Semotiuk K, Permaul JA, Yung EM, Blaine S, Dicks E, Warner E, Rothenmund H, Esplen MJ, McLaughlin J. Hereditary Colorectal Cancer Screening: A 10-Year Longitudinal Study Following

an Educational Intervention. North American Primary Care Research Group. November 2017. Oral presentation by J Carroll.

Permaul JA, Semotiuk K, Warner E, Blaine S, Dicks E, Esplen MJ, McLaughlin J, Rothenmund H, Yung E, Carroll JC. Hereditary Colorectal Cancer Screening Behaviour and Knowledge in Family Physicians and their Patients: 10 Years Following Intervention. Department of Family and Community Medicine Conference, Walter Rosser Research Day, University of Toronto, April 2016. Poster presentation by J Permaul.

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