Research Article

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Personalized Medicine

Universal tumor screening for lynch syndrome: perspectives of patients regarding willingness and informed consent

Anusree Subramonian[1], Doug Smith[2], Elizabeth Dicks[1], Lesa Dawson[3,4], Mark Borgaonkar[5] & Holly Etchegary*[,1]

[1]Clinical Epidemiology, Faculty of Medicine, Memorial University, St John's, NL, Canada
[2]Patient Partner, St. John's, NL, Canada
[3]Gynecologic Oncology, Women's Health & Genetics, Faculty of Medicine, Memorial University, St John's, NL, Canada
[4] Women's Health and Genetics, Eastern Health, St John's NL, Canada
[5]Gastroenterology, Faculty of Medicine, Memorial University, St John's, NL, Canada
*Author for correspondence: Tel.: 709-864-6605; holly.etchegary@med.mun.ca

Aim: Lynch Syndrome is associated with a significant risk of colorectal carcinoma (CRC) and other cancers. Universal tumor screening is a strategy to identify high-risk individuals by testing all CRC tumors for molecular features suggestive of Lynch Syndrome. Patient interest in screening and preferences for consent have been underexplored. **Methods:** A postal survey was administered to CRC patients in a Canadian province. **Results:** Most patients (81.4%) were willing to have tumors tested if universal tumor screening were available and were willing to discuss test results with family members and healthcare professionals. The majority (62.6%) preferred informed consent be obtained prior to screening. **Conclusion:** Patients were supportive of universal screening. They expected consent to be obtained, contrary to current practice across Canada and elsewhere.

First draft submitted: 10 March 2020; Accepted for publication: 17 June 2020; Published online: 2 September 2020

Keywords: colorectal cancer • lynch syndrome • patient oriented research • reflex testing • universal tumor screening

Colorectal carcinoma (CRC) is the third most common malignancy in the world [1], with 20–30% potentially having a genetic or familial origin [2]. Lynch Syndrome (LS) is the most common type of inherited CRC, accounting for 3–5% of all cases. LS is caused by mutations in the mismatch repair genes (MMR) namely, *MLH1*, *MSH2*, *MSH6* and *PMS2* [3,4]. Individuals with pathogenic variants in these mutations have up to a 78% lifetime risk of developing CRC. Higher rates of extra-colonic cancers, including endometrium, renal pelvis, ureter and small bowel [5,6] are also observed. Thus, early identification of high-risk individuals is important for cancer prevention and improved health outcomes. High-risk individuals were historically identified using Amsterdam and Bethesda guidelines, which rely on family history and age of cancer onset [7–10]. However, these guidelines have been found to leave many unidentified [11–13]. More recent methods for identifying high-risk individuals rely on the genetic and molecular basis of LS [14] and include immunohistochemistry (IHC) and microsatellite instability (MSI) testing [15,16].

Universal tumor screening for LS (also called reflex testing) is the strategy of screening every newly diagnosed CRC patient using MSI or IHC testing, irrespective of family history [17]. For those testing positive in the initial screen, germline testing is then done to confirm the diagnosis of LS. The initial recommendation for universal screening by the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group (EWG) was quickly followed by recommendations from various national and international organizations [15,16,18–23] and is a cost-effective method for identifying LS carriers [24–26].

However, the uptake of universal screening is moderate at best [17,27,28]. In Canada, an integrated approach to LS screening is lacking [29,30]. In Newfoundland and Labrador (NL), where the incidence of familial CRC is the highest in the world [31], a screening approach based on family history was inefficient [32]. This is an important

issue, not only at a patient level where adequate risk identification and preventive surveillance are lacking, but also at a population level, with high mortality and morbidity of LS-associated malignancies.

The perspectives of patients about universal screening programs are critical. The success of screening programs is reliant on patient and family engagement with follow-up diagnostic testing and adherence to cancer surveillance [33,34]). Practical components of tumor screening programs can also be informed by engaging with patients. Patient perceptions on informed consent for universal screening is relatively under-researched. The current practice in tumor screening programs is nonrequirement of consent [29,30]. Thus the Wilson-Junger criteria, a ten-item list to be met by a screening program before being established as a public health measure – one key item being ensuring informed choice and patient autonomy – would appear unmet [35,36]. Research examining patients' perspectives on universal screening revealed a positive attitude toward screening and a willingness to communicate the results to family members and healthcare providers [37–39]. However, limited research has explored patient preferences for consent in this context.

The objective of this patient-oriented research was to explore CRC patients' attitude and interest in testing, willingness to communicate with healthcare professionals and family members about test results, and their perspectives on the need for, and preferred mode of informed consent.

Methods

Following institutional ethics approval, a cross-sectional, postal survey was administered to CRC patients.

Participants

The target population was all living patients in NL diagnosed with CRC. The study team was advised that the years 2014–2016 contained the most up-to-date data and patients not recently contacted for a Cancer Centre study. Thus, all living patients diagnosed with CRC from 2014 to 2016 were eligible irrespective of age, gender and stage of tumor. Participants were identified from the Provincial Cancer Registry; mortality clearances were obtained from the Newfoundland and Labrador Center for Health Information (NLCHI) prior to survey administration.

Survey design & development

The 32-item survey had three sections:knowledge and understanding of inherited CRC and universal screening; attitude and opinions about screening, including the need for and preferred form of informed consent; and personal, demographic and family history information. With permission from the author, some questions were adapted from a US survey examining patient perspectives on the benefits and barriers of universal screening [38]; other items were developed by the research team. Demographic variables including date of birth, sex, date of diagnosis, stage of tumor at diagnosis and first three digits of postal code were extracted from the provincial cancer registry and merged with the survey responses. This study had a patient partner on the research team (DS) to ensure a patient perspective was included in the study design and methods. Initial drafts of the cover letter and survey were reviewed by the patient partner for language, flow and level of respondent burden. Small revisions were made following his review and the survey was reviewed by the larger project team.

Survey administration

The survey booklet and return envelope were mailed to participants in two phases: an initial mail out, and a reminder 8 weeks later. Several strategies were adopted to increase the response rate of the survey including a postage paid return envelope, a reminder mailout, a gift card prize draw for completing the survey and colored survey booklets [40,41].

Data collection & analysis

Returned surveys were entered into SPSS [42], and double-checked by hand for data entry errors. Item-level descriptives (e.g., frequencies, means, response ranges) were also checked to ensure data entry accuracy. Missing data were coded as such; data were analysed using descriptive and inferential statistics. Survey responses 'strongly agree' and 'agree' were pooled together to indicate a positive response in descriptive results. Similarly, response 'strongly disagree' and 'disagree' were pooled together to indicate a negative response to the survey items. While variation exists in the literature, there is evidence that Likert scale data can be considered interval data [43], utilizing means and standard deviations in analyses and that was the approach employed in this study. Items measuring similar themes of attitude and communication were pooled to create an attitude and a communication scale

to conduct bivariate and multivariate analyses. Scales were created by summing items together (first attitude items, then communication items) and taking the average; the internal consistency measured using Cronbach's alpha. Willingness to undergo screening and preferences on the need for informed consent were primary outcome variables. These scales and other items were analyzed using further analyses including multiple regression to identify the predictors of willingness to take part in a tumor screening program, as well as informed consent preferences. All analyses were performed using SPSS V23 [42].

Results

Survey packages were mailed to 698 eligible patients with a diagnosis of CRC; 318 surveys were returned giving a response rate of 47.6% (318/668). The demographic and clinical characteristics of the responders are described in Table 1. The mean age of the responders was 69 years (SD = 9.7; range 43–94); 55.7% were male. Among them, 168 (52.8%) lived in rural areas and the highest level of education for 51% of respondents was high school diploma or lower. Most participants were married or living with a partner (71%) and had at least one child. Survey respondents were younger (mean age = 69) than nonrespondents (mean age 71.6 years, $t = 3.15$; $p < 0.05$). No significant differences were observed between the two groups regarding sex, area of residence, year of diagnosis and stage of tumor (Table 2).

Knowledge

Two items explored participants' knowledge about inherited forms of CRC and universal tumor screening. Participants reported low levels of knowledge for both items. Around 30% of the participants had never heard about inherited forms of CRC, while 83.1% had never heard of universal screening for LS prior to this survey.

Attitude towards universal screening

Participants agreed that screening would be useful for identifying high-risk individuals and believed their family could benefit from it (Figure 1). Most of the participants agreed that the result of a screening test would help them plan their future (77%) and that the test should be available for anyone with CRC and wishes to have information about his/her inherited risk (92%). Items measuring attitude were pooled to create an attitude scale (ATT) with an internal consistency of 0.631 (Cronbach's α) (Table 3). This is slightly low; however, given the pilot nature of this work and the limited literature about patient preferences in this area, the attitude scale was retained for analyses. The mean score of the scale was 3.8 (SD = 0.5), highlighting participants' largely positive attitude toward screening.

Communication

Nearly all respondents (94%) were willing to discuss their test result with doctors and other healthcare professionals to guide future treatment (Figure 2). A vast majority (n = 300; 94.3%) indicated they would talk to their family members about the test results. Sixty one percent of the respondents thought they would need help from a healthcare professional to discuss the results with their family. Among the participants, 242 (76.2%) said they understood the implications a screening test could have on their family and most of them (90.5%) agreed that they would encourage their family members to learn more about the implications as well. Items pertaining to communication were pooled to create the communication scale (COMM) with an internal consistency of $\alpha = 0.703$ (Table 3). The mean score of the COMM scale was 4.34 (SD: 0.49) indicating high intentions to communicate. Participants with higher levels of knowledge about inherited forms of CRC were more likely to communicate with family and healthcare professionals about tumor testing ($r = 0.153$, $p < 0.01$). Participants with higher education levels ($F(2, 302) = 9.68$, $p < 0.01$), and those living in urban areas ($t(307) = 2.93$, $p < 0.05$) had greater intentions to communicate their test results.

A positive correlation was observed between the ATT and COMM scales, indicating that the more positive the attitude toward universal screening, the more likely they were to indicate an intention to communicate with healthcare providers and family members ($r = 0.492$; $p < 0.01$). Younger participants had more positive attitudes toward tumor testing ($r = -0.117$; $p < 0.01$) and were more likely to indicate intention to communicate with family members and healthcare professionals about it ($r = -0.134$; $p < 0.01$).

Willingness to undergo screening

The outcome variable 'willingness' describes the participants' willingness to undergo a universal tumor screening test if it was offered to them. The majority (81.4%) of participants indicated that they would be willing to have

Table 1. Demographic and clinical Characteristics of the participants (n = 318).

Categories	n (%)
Sex:	
– Male	177 (55.7)
– Female	141 (44.3)
Age:	
– Mean age (SD)	69 (9.7)
– Range	43–94
Area of residence:	
– Rural	168 (52.8)
– Urban	150 (47.2)
Highest level of education:	
– High School certificate or lower	162 (50.9)
– Trade school/nonuniversity or some university	119 (37.4)
– Bachelor's degree or higher	28 (8.8)
Current marital status:	
– Single	18 (5.7)
– Married or living with a partner	227 (71.4)
– Divorced/separated	19 (6.0)
– Widowed	46 (14.5)
Number of children:	
– None:	18 (5.7)
– 1–3	218 (68.6)
– 3–5	55 (17.3)
– >5	17 (5.3)
Year of diagnosis:	
– 2014	56 (17.6)
– 2015	120 (37.7)
– 2016	142 (44.7)
Stage of tumor:	
– I	33 (10.4)
– IIA	50 (15.7)
– IIB	4 (1.3)
– IIC	4 (1.3)
– IIIA	9 (2.8)
– IIIB	51 (16.0)
– IIIC	11 (3.5)
– IVA	13 (4.1)
– IVB	2 (0.6)
Family history of cancer (self reported):	
– Yes	267 (85.9)
• Parent	134 (42.1)
• Children	25 (8.1)
• Spouse	47 (15.2)
• Sibling	139 (45.0)
• Others	93 (30.0)
– No	44 (14.1)

†Information regarding the highest level of education was missing for nine participants.
‡Information regarding the marital status was missing for eight participants.
§Information regarding the number of children was missing for ten participants based on American Joint Committee on Cancer (AJCC) guidelines, Seventh Edition.
¶Information on stage of tumor is missing for 44.3% of the participants.

Table 1. Demographic and clinical Characteristics of the participants (n = 318) (cont.).

Categories	n (%)
Family history of colon cancer (self reported):	
– Yes	137 (44.3)
• Parent	43 (13.9)
• Children	9 (2.9)
• Spouse	12 (3.9)
• Sibling	55 (17.8)
• Others	57 (18.4)
– No	172 (55.7)

†Information regarding the highest level of education was missing for nine participants.
‡Information regarding the marital status was missing for eight participants.
§Information regarding the number of children was missing for ten participants based on American Joint Committee on Cancer (AJCC) guidelines, Seventh Edition.
¶Information on stage of tumor is missing for 44.3% of the participants.

Table 2. Comparison of responders and nonresponders of the survey.

Variable	Responders	Nonresponders	Test
Age	Mean = 69.1	Mean = 71.6	Mean difference = -2.51 ($t = -3.15$; $p < 0.05$)
Sex	Female 44.3%	Female 42.6%	^{2} 0.206 p -0.650
Area of residence	Rural 52.8%	Rural 52.1%	^{2} 0.036 p -0.849
Year of diagnosis	2014 17.6%	2014 15.7%	^{2} 0.0448 p -0.799
Stage of tumor†	Stage I – 10.3%	Stage I – 10%	^{2} 7.036 p -0.722

†Stage of tumor information missing for 45.1% individuals.

Table 3. Components and characteristics of Attitude and Communication scales.

Scale	Items included	Mean score (SD)	Range	Cronbach's α
ATT	4. Universal tumor screening would be useful for identifying high risk individuals. 5. My family could benefit from this test. 8. The results could help plan my future. 12. The test should be available to anyone who has had colon cancer. 6. I would not take a tumor screening test it if I had to pay for it. † 7. People should not have their tumors screened if they don't ask for the test.† 9. I would be worried that universal tumor screening would affect my ability to get health or life insurance in the future.† 10. I am concerned about any discrimination I could face based on the test result.† 11. I do not want to know about any genetic risks I might have.†	3.8 (0.5)	2.56–5.0	0.631
COMM	14. Would you be willing to discuss your test result with any of your doctors or other health care providers to guide your future care or treatment? 15. I would talk to my family members about the results of a tumor screening test done on my tumor. 18. I would encourage my family members to learn more about the implications of a tumor screening test done on my tumor.	4.34 (0.49)	2.33–5.0	0.703

†These items were reversely coded to reflect a positive attitude toward universal screening.
ATT: Attitude scale; COMM: Communication scale; SD: Standard deviation.

their tumors screened. ATT and COMM scores were positively correlated with willingness to undergo screening ($r = 0.381$, $p < 0.01$ and $r = 0.581$, $p < 0.01$, respectively). In the initial bivariate analyses, several other variables were also found to be significantly associated with the willingness to undergo universal screening namely, age, family history of CRC and the number of children. (Table 4). These variables, as well as ATT and COMM scales were included in the multivariate analysis. A multivariable regression model was developed using Generalized Linear Models. The final regression model included age, ATT score, COMM score and family history of CRC with all four variables adding significantly to the model ($p < 0.05$) (Table 5). Participants with high attitude scores were more

Figure 1. Attitude of patients regarding universal tumor screening.

willing to undergo screening (OR: 1.21; 95% CI: 1.02–1.43). Those with high communication scores were over two-times more likely to indicate willingness to have their tumors screened (OR: 2.14; 95% CI: 1.8–2.5). A positive family history of CRC slightly lowered inclination to get screened for LS, when age, attitude and communication were considered (OR: 0.858; 95% CI: 0.74–0.93).

Need & preferred form of consent

Participants' perspectives regarding the need for, and preferred form of informed consent are shown in Figure 3. The majority of respondents (62.6%) were in favor of consent being obtained for universal tumor screening. They indicated that the consent can be taken at the same time as the surgical consent (63%), and 51.6% preferred a written consent.

Regression analyses revealed no relationship between the need for consent and participants' willingness to undergo screening (data not shown). People with a bachelor's degree or higher were 5.9-times more likely to prefer consent compared to those with high school level education or lower (95% CI: 1.34–26.55; $p < 0.05$). Patients living in urban areas were 1.7-times more likely to think a separate consent was required than those in rural areas (95% CI: 1.02–2.86; $p < 0.05$). Age, sex and attitude toward universal screening were not predictive of preference for consent.

Informing & educating patients

While participants wanted to be informed about universal screening, their preferences for who spoke to them about it varied widely with over half (52.5%) indicating any of their healthcare professionals could talk to them about screening (Figure 4). Majority of the study participants (59.1%) were of the opinion that patients should be informed about tumor testing when they first receive their cancer diagnosis. Most participants (91.5%) agreed that

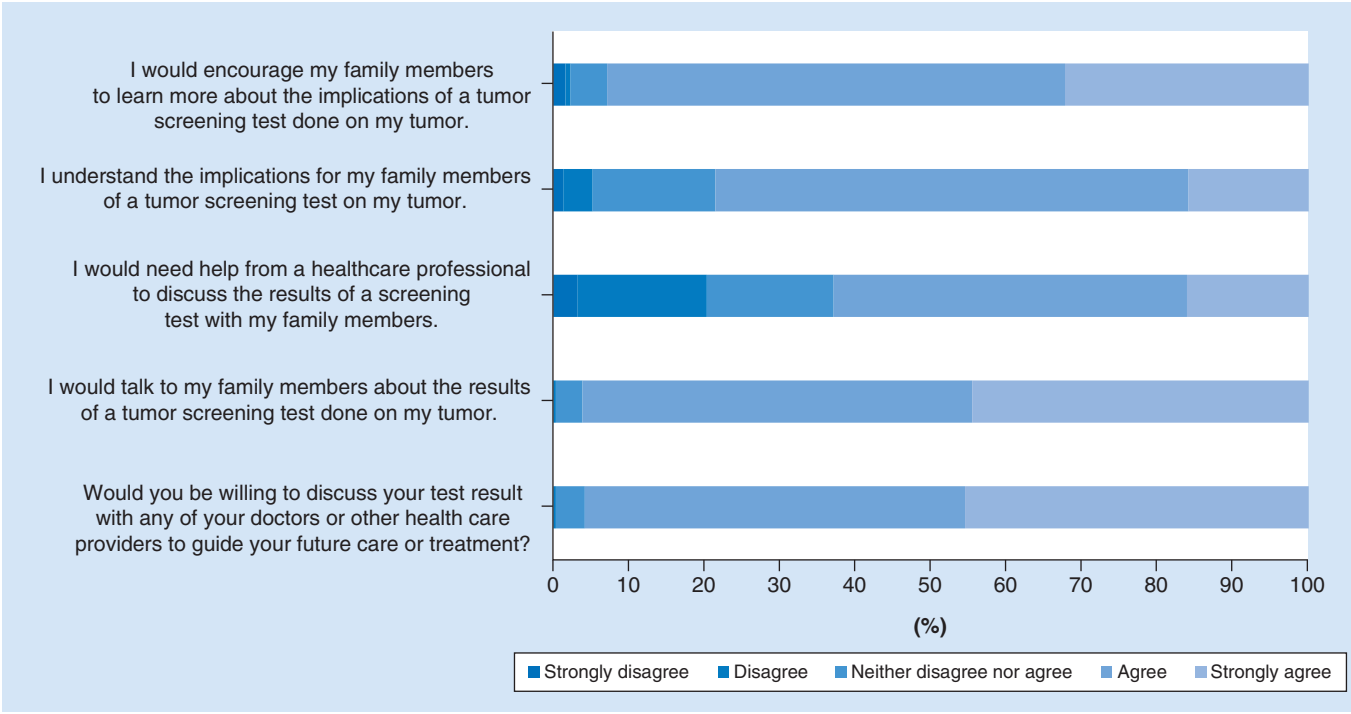

Figure 2. Participants' intention to communicate with their families and healthcare professionals.

Table 4. Analysis of willingness outcome with demographic variables, Attitude and Communication scales.

Variable	Willingness		
	Mean (SD)	Test statistic (df)	p-value
ATT	3.8 (0.5)	r = 0.381‡	<0.01
COMM	4.34 (0.49)	r = 0.581‡	<0.01
Age		r = -0.117†	0.046
Sex:			
– Male	4.20 (0.816)	t (310) = 1.104	0.271
– Female	4.30 (0.751)		
Area of residence:			
– Rural	4.20 (0.782)	t (310) = 1.143	0.254
– Urban	4.30 (0.795)		
Family history of colon cancer:			
– No	4.14 (0.840)	t (305) = 2.92‡	0.004
– Yes	4.40 (0.682)		
Level of education:			
– High school certificate or lower	4.17 (0.752)	F (2, 304) = 2.381	0.094
– Trade school/some university	4.38 (0.751)		
– Bachelor's degree or higher	4.29 (0.937)		
Marital status:			
– Single	4.17 (0.707)	F (3,304) = 2.253	0.082
– Divorced/separated	4.53 (0.772)		
– Widowed	4.02 (0.856)		
– Married/Living with a partner	4.28 (0.770)		
Number of children		r = -0.137†	0.017

†Correlation is significant at the 0.05 level (2-tailed).
‡Correlation is significant at the 0.01 level (2-tailed).
ATT: Attitude scale; COMM: Communication scale; df: Degrees of freedom; SD: Standard deviation.

Table 5. Multiple regression analysis of predictors of willingness to undergo screening.

Variable	Willingness to undergo screening		
	OR	95% CI	p-value
Communication scale (COMM)	2.14	1.805–2.553	0.000
Attitude toward screening scale (ATT)	1.21	1.028–1.438	0.022
Family history of colon cancer not present	0.858	0.740–0.994	0.041
Family history of colon cancer present	Ref	Ref	–
Age	0.992	0.984–0.999	0.027

they needed written educational materials about universal screening and the risk of inherited CRC, and that they be provided before the day of the surgery (53%).

Discussion

This study explored the perspectives of patients with CRC in a Canadian province toward universal tumor screening for LS. The project was conceived in response to discussions about establishing a tumor screening program in this jurisdiction. Findings suggest patients with CRC have positive attitudes and intentions toward universal screening. In general, they prefer a written informed consent be obtained prior to screening.

Study participants had low levels of knowledge regarding inherited forms of CRC and universal screening, in line with similar studies [44,45]. These findings underscore the critical need for the development of patient-centered educational materials about universal screening as part of program planning.

Study revealed very positive attitudes toward universal tumor screening, consistent with literature that report on patients' attitudes toward universal tumor screening specifically [38,44] and genetic screening tests generally [33,46–48]. An overwhelming majority of the participants were willing to have their tumors screened if a universal screening program were available to them, consistent with existing literature [44,46,48–50]. Given this study measured hypothetical willingness to take part in tumor screening, it is not known if the positive attitudes observed in this study would translate into actual tumor screening uptake [51]. However, the favorable attitude of patients who had CRC is a necessary first step in the creation of a local tumor screening program.

Nearly all participants were willing to discuss their test with healthcare professionals to guide future treatment, as well as to share test results with family members. These findings are promising, but the literature has identified several barriers to communication with family about inherited risk such as pre-existing relationship dynamics within the family, uncertainty of the risk and varied understanding of the implication of the genetic risk on the relatives [52]. Several studies have explored various approaches to facilitate communication with family members regarding genetic risk, including providing the patients with printed informational materials and subsequent follow up support [53], 'family mediated approach'[54] and telephone-based, two-step approach [55]. These strategies, coupled with the findings and insights from our study, could help formulate counseling and communication policies that would benefit patients and aide them in communicating their results to family members. This in turn could facilitate genetic screening of relatives, and ultimately, help mitigate the mortality and morbidity of LS.

Contrary to current practice, majority of patients supported informed consent for universal screening. This finding is consistent with the few other studies about patient perspectives on consent in this context [56,57], but is in contrast to the perspectives of some healthcare providers and current practice [29,58–60]. There are no universally-accepted guidelines for consent protocols for universal screening for LS, and it remains a subject of debate in the literature [15,17,58,61]. Debate exists about protecting patient autonomy, but also the potential for stress and anxiety in those patients who ultimately test negative [29,62]. Given the need for cascade testing of family members in the event of a positive screen and positive confirmatory tests, patient and family preferences for consent protocols are a critical piece of information in the planning of a tumor screening program.

Study findings suggest that patients prefer a written informed consent taken at the same time as surgical consent. These findings have practical value in the implementation of a screening program, but they also raise logistical concerns regarding the content of consent materials and the role of healthcare professionals in obtaining consent, particularly in the existing climate that tends toward nonrequirement of informed consent in screening for LS. Serious thought will need to be taken by decision makers responsible for planning tumor screening programs about consent protocols that are acceptable to patients and providers. In the light of present findings of patient preference

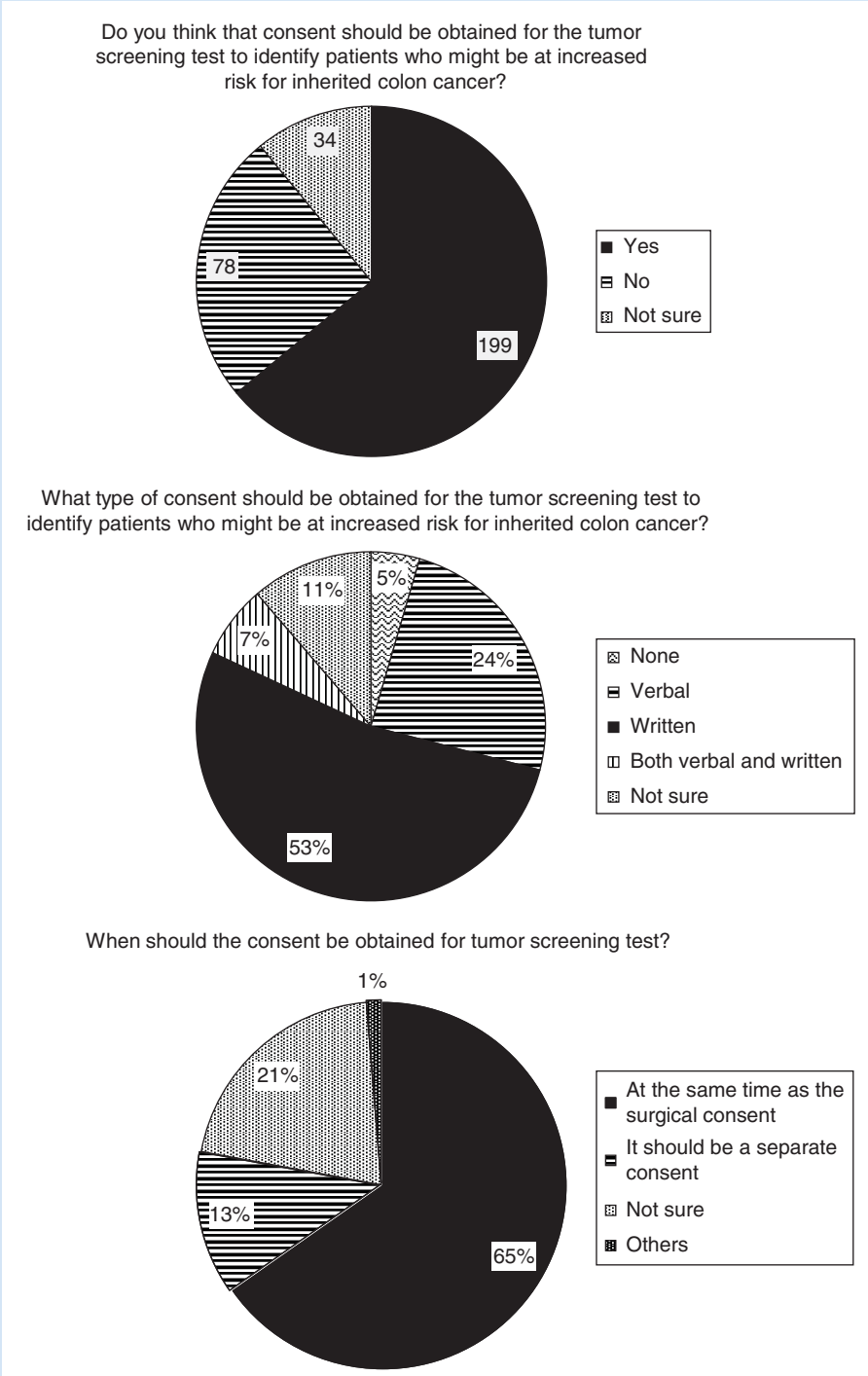

Figure 3. Participant's responses on the need for and form of informed consent.

for consent, an opt-out strategy could be a practical suggestion [29]. The additional burden of obtaining consent could add increased demand on healthcare providers, raising another barrier to implementation. Family physicians, while acknowledging their potential role, have expressed concerns about their own lack of knowledge and training about genetic screening tests and the need for additional materials that would support them in discussing the implications of universal screening with their patients [63,64]. Ensuring informed choice and patient autonomy is a

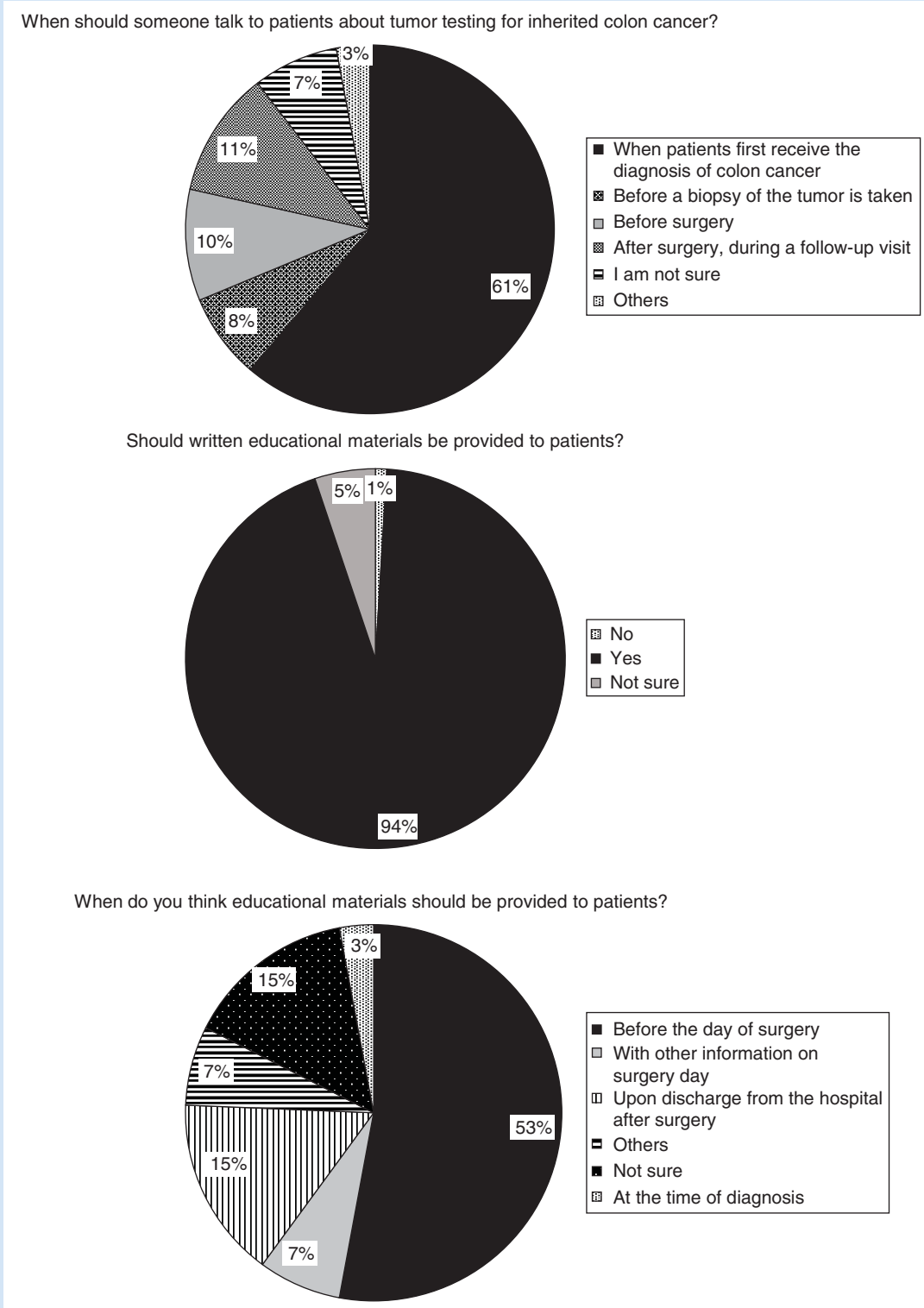

Figure 4. Participant's preference on informing and educating patients about universal tumor screening.

critical criterion in establishing a screening program [35,36], which can me met by obtaining informed consent form the patients.

Participants wanted to be informed about screening for LS at the time of diagnosis by almost any healthcare professional. Given the scarcity of genetic counsellors across Canada and the long wait times for counselling services, this finding has practical implications [30,32]. Other healthcare professionals such as primary care physicians, nurses and surgeons could have a role in educating patients about tumor testing, and guidelines to assist healthcare professionals in this role have been described [63,65–67]. Patient preferences observed in this study support that role. However, as noted, healthcare providers may not feel confident communicating with patients about tumor testing, and access to training and support will be critical if providers are to accommodate patients' communication preferences.

Most patients indicated educational materials should be provided about universal screening and LS prior to screening tests. Educating patients and creating awareness about tumor screening is endorsed by healthcare professionals and policy makers [17,29,44], but, to our knowledge, no guidelines or materials are currently accepted and used in Canada. EGAPP guidelines recommend providing educational materials for all CRC patients, as well as their relatives [15]. The low levels of prior knowledge and awareness in the current study population and others stress the importance of informing and educating patients. Facilitation of communication with the aid of educational materials could be useful in cascade screening of family members resulting in early identification and subsequent preventative measures [68].

This is the first study conducted in an Eastern Canadian province about patients' attitudes toward universal tumor testing for LS. Our results are consistent with the studies conducted in the US and elsewhere and reveal the importance of understanding patient perspectives on tumor screening and highlight practical considerations for program planners and decision makers [37,38,44].

Findings should be interpreted in light of study limitations. The survey was not pilot tested for formal validation and reliability testing. Within the context of the short study duration and the need to collection patient opinion data before any tumor testing program started in the province, formal validation could not be completed in a timely manner. However, the study's patient partner helped identify important content area for the survey and fully reviewed the instrument, providing some face validity. Given the lack of patient opinion data in the literature on tumor testing, we believe the results have important descriptive value. The eligible participants from the cancer registry included patients diagnosed from 2014 to 2016. While no limits were set on tumor stage, sex or age, this did exclude the views of patients diagnosed before or after that period. It is not known if attitudes or willingness to engage in universal screening would be different if patients were diagnosed in other years. Those who responded to the survey could have had more favorable attitudes than the nonresponders, thereby overestimating our findings and lowering the external validity of the study. However, there were few significant differences in the characteristics of responders and nonresponders. While adequate, the internal consistency of the ATT scale was low, and there were more neutral responses in the reverse-scored negative attitude items than in the positive items, raising questions about the usefulness of combining these items into a single attitude score. Future research including formal scale validation would be needed in order to create a robust attitude scale. Finally, it is possible the sequencing of certain survey items asked before the need for informed consent could have primed the participants about expectations for consent and influenced their responses. Given the pilot nature of this work, and the need to collect patient opinion data before any tumor testing program started in the province, the results have descriptive value.

Despite these limitations, the high response highlights the interest of the population in this topic and is a strength of the study. This project adds to the knowledge base and provides important patient perspectives that should be helpful in planning a tumor screening program. While limited in years, the inclusion of all patients from the cancer registry diagnosed during the specified time period helped to avoid sampling bias. Findings have real world implications for decision makers and program planners who are implementing a universal screening program for LS. Patients with CRC expressed positive attitudes and a willingness to undergo tumor screening. Patients' desire for informed consent and preferences for when it should be offered and by whom could also assist in developing educational materials and consent protocols for tumor screening.

Future perspective

The findings of this study could have real world implications in designing and implementing a universal screening program for LS. The findings on patients' desire for informed consent could inform the development of educational materials and consent protocols in the province. Further research is needed to validate the patient survey and use it

to explore the perspectives of stakeholders in other parts of the country. It could also be worthwhile to analyze the positive and negative attitude items separately. The multivariate analysis revealed a strong correlation between the communication score and willingness to undergo screening. However, the relationship between a positive attitude score with screening willingness was more muted (potentially signifying conflict between attitudes). If explored at the individual response level, future research that better understands that potential attitudinal conflict could reveal useful information for counseling and consent purposes. Ultimately, such work would assist in a deeper understanding of patient perspectives that could help healthcare professionals in patient education as well as to accommodate patient preference in informed consent protocols.

Future studies focusing on the perspectives of the family members of colon cancer patients, and on that of patients with LS-associated extracolonic cancers could also be undertaken.

Summary points

- Lynch syndrome is the most common type of hereditary colon cancer. Universal tumor screening is a strategy by which all newly diagnosed colorectal carcinoma patients are tested for molecular features suggestive of Lynch Syndrome to identify high risk individuals.
- A survey study exploring the perspectives of colorectal cancer patients regarding patient interest in screening and their preferences on informed consent was done on Newfoundland and Labrador, Canada.
- The participants of the survey expressed willingness to undergo tumor testing if such a program was available. Most of the participants were willing to share the test results with family members and healthcare professionals.
- Contrary to current practice, the participants preferred an expressed consent to be obtained prior to tumor screening.
- Findings could help implement universal tumor screening in the province and elsewhere in Canada.
- Importance should be given to developing informed consent protocol and educational materials. Training primary care providers could be useful, as they can play a key role in informing and educating patients.

Acknowledgments

The authors thank S Ryan, Provincial Cancer Registry for help with study recruitment and C Simmonds for help with survey administration.

Financial & competing interests disclosure

This study was funded through Dean's Innovation Fund, Faculty of Medicine, Memorial University (PI Etchegary). Subramonian was supported through a patient-oriented student fellowship, NL SUPPORT Unit, Memorial University. AS is a CADTH employee. The current work was unrelated to her employment, and CADTH had no role in the funding, design, or oversight of the work reported. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

Ethical conduct of research

The study was approved by the Newfoundland and Labrador Health research ethics Board (HREB), ref no: 2016.277. The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations.

Data sharing statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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