*Original Research*

# Family physicians' and trainees' experiences regarding cancer screening with patients with intellectual disability: An interpretive description study

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## Abstract

People with intellectual disability receive breast, cervical, and colorectal cancer screening at lower rates relative to the general population, although the reasons for this disparity are largely unknown. Research, both with the general population and specific to people with intellectual disability, has revealed that a family physician's recommendation for cancer screening or continuity of primary care may increase screening rates. We interviewed family physicians and family medicine trainees regarding their experiences recommending cancer screening to patients with intellectual disability. We concluded that the decision to recommend cancer screening is complex, and includes physicians weighing their clinical judgement as to the best provision of care for patients with a patient's eligibility for screening, while continuing to respect patients' autonomy. This patient-physician interaction occurs within the larger medical environment. Further research with experienced family physicians is warranted to better understand this complex phenomenon.

## Keywords

cancer screening, family medicine, intellectual disability, primary care, qualitative research

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## Introduction

Cancer screening improves patient outcomes through early detection of cancer. Women with intellectual disability do not receive screening for breast or cervical cancer at rates comparable to the general population. For instance, Canadian researchers have reported that women with intellectual and developmental disability were less likely to have had a Pap test in the previous 3 years (approximately 34% of women with intellectual and developmental disability in this time period compared to approximately 67% of women without intellectual and developmental disability) and women with intellectual and developmental disability aged 50 to 69 years old were less likely to have received a mammogram in the previous 2 years (approximately 42% of women with intellectual and developmental disability in this time period compared to approximately 60% of women without intellectual and developmental disability; Cobigo et al., 2013). People with intellectual disability also face disparities in accessing colorectal cancer screening; in a study by researchers in Ontario, Canada, individuals with intellectual disability were less likely to have received a faecal occult blood test for colorectal cancer in the previous 2 years relative to the general population (approximately 18% for adults with intellectual and developmental disability compared to approximately 26% for adults without intellectual and developmental disability; Ouellette-Kuntz et al., 2015). More recently, a nation-wide study of individuals eligible for breast (adjusted odds ratio (aOR), 0.403; 95% confidence interval (CI), 0.397–0.410; Shin et al., 2020a), cervical (aOR, 0.25; 95% CI, 0.25–0.26; Shin et al., 2018), and colorectal (aOR, 0.610; 95% CI, 0.599–0.621; Shin et al., 2020b) screening in South Korea found that having an intellectual disability was associated with receiving significantly lower cancer screening rates for all three forms of screening. It is possible that this disparity is due to family physicians are not promoting cancer screening to the same degree as patients without intellectual disability.

Primary care providers, including family physicians, are frequently the main point of contact for entry into the health system in many countries, including Canada, and facilitate access to cancer screening. For example, Coughlin et al. (2005) reported that a primary care provider's recommendation for cancer screening among patients in the general population is a key determinant of whether an individual receives screening. More recently, and specific to the intellectual disability population, Plourde et al. (2018) report that among women with intellectual disability, women with a higher continuity of primary care were more likely to have received breast and cervical cancer screening within the recommended time period.

The study reported here was part of a mixed methods doctoral thesis conducted by the first author; the larger project also included a quantitative phase, reported elsewhere (Breau et al., 2020). The primary research question guiding the qualitative phase of the study was: What are the experiences of primary care providers in recommending cancer screening to their patients with intellectual disability? A secondary aim was to explore the factors related to participants' decision to recommend or not recommend cancer screening to their patients with intellectual disability.

## Methods

In this study, we used an interpretive descriptive methodology, as developed by Thorne (2008). This approach draws on disciplinary knowledge and is an approach consistent with conducting research in the applied health field. First, open coding, using participants' own words to name the codes, is conducted. Then, codes are combined to generate a secondary level of coding. The aim of the analysis is to suggest an answer to a clinical problem.

## Participants and setting

Participants were 2 family physicians who had completed their medical training and 10 family medicine trainees enrolled at a large public research-intensive university in western Canada. All trainees were medical doctors in the first year of a 2-year family practice residency programme. Completion of the 2-year training is required for trainees to practice independently as family physicians in Canada.

*Participant recruitment.* The two experienced family physicians were recruited through the cross-sectional survey phase of the study, by indicating in their survey responses that they would be willing to be contacted for interview. To expand the data set, we obtained permission from the university Faculty of Medicine Research Access Committee to send an email letter of invitation to current family medicine trainees (a total of 154 trainees). In total, 11 trainees replied to the email invitation and contacted the first author via email: ultimately 10 trainees provided informed consent and participated in an interview.

## Procedure

All interviews were conducted via telephone at a time convenient to participants. Phone interviews were selected as the method for data collection because participants were based across a wide geographic region in our province, including both urban and rural areas. We wished to include participants from rural and remote areas of the province with the understanding that these regions may have less accessible population-based screening programmes. The study research assistant, a masters-prepared nurse and experienced qualitative interviewer, conducted 11 of the interviews; the remaining interview was completed by the first author.

*Instruments.* An open-ended interview guide was developed by the first author to guide the open-ended interviews. In addition to gathering interview data that might place the quantitative survey data into the wider context of screening recommendations for all three types of cancer in the general population as well as for patients with intellectual disability, our interview guide explored potential factors participants consider before making a recommendation. We specifically asked each participant for their experience providing general primary care to patients with intellectual disability, and then elicited their experiences recommending breast, cervical, and colorectal cancer screening, both in general and specific to patients with intellectual disability. The interview guide was sent in advance in order to allow participants to reflect on their experiences prior to the interview. Interviews ranged in length from 30 to 40 minutes. The interviews were transcribed verbatim by a professional transcriptionist. In order to assist with preserving confidentiality, all participants were given an alpha numeric code, and all potential identifiers were removed, such as other health professional names, hospital or clinic names, and geographic locations. All confidential information (i.e., names, alpha numeric identifiers) was password-protected, and stored on secure servers.

## Data analysis

The first author analysed the data from the open-ended interviews using the interpretive description approach, as described by Thorne (2008). First, she coded the first two interview transcripts using open coding, in which participants' key words are used as the name of the initial code. This led to a provisional coding framework with four tentative themes emerging. She then applied this framework to two more interviews and then reviewed the excerpts for each code. This method resulted in a reconfiguration of the themes and coding framework. This revised coding framework was subsequently applied to the fifth and sixth interviews. Because at this stage, the revisions to the coding framework were minor, she then used this framework to code the remaining six interviews. By the end of coding all 12 interviews, there were sufficient commonalities to detect patterns in the data.

### *Rigour of study*

Methodological credibility was considered according to four criteria outlined by Thorne (2008): epistemological integrity, representative credibility, analytic logic, and interpretive authority. Epistemological integrity was maintained by using a pragmatic perspective consistent with the mixed methods approach used in the overarching study (Cresswell and Plano Clark, 2011) and allows researchers to choose the methods best suited to answering the research problem. While the quantitative phase explored the role of attitudes on cancer screening recommendations, this approach allowed a more detailed exploration of the role of family physicians in recommending cancer screening, from the perspective of family physicians themselves, to emerge during the interviews.

Representative credibility is analogous to internal validity in quantitative research (Holloway and Wheeler, 2010; Mayan, 2009), and is determined by evaluating whether the findings make sense, and whether the researcher's interpretation of the data is representative of the sample of participants. Credibility was ensured in this study by using purposive sampling: the first author sought to recruit both male and female physicians from a wide range of geographic areas. Credibility was enhanced through data triangulation in this study, by gathering quantitative data surrounding participants' experience, in addition to gathering qualitative data through open-ended interviews. Analytic logic was maintained in this study by keeping an audit trail. The first author kept a reflexive journal and wrote memos during the analytic process, which also included creating diagrams to demonstrate relationships between various themes, and how they informed her interpretation of the data. Finally, interpretive authority was maintained by noting how analytic data related to both previous research and the findings from the survey phase. These steps helped ensure that the interpretation of the data and the conclusions drawn from it, were credible and trustworthy, and accurately represented the participants' experiences (Holloway and Wheeler, 2010).

### *Ethical approval*

Ethical approval was sought from the university's Behavioural Research Ethics Board. In addition, ethical approval was also received from the university Faculty of Medicine Research Access Committee, which is a requisite additional step for researchers wishing to conduct research with Faculty of Medicine students or trainee family physicians.

Written informed consent was obtained from all interview participants. As instructed in the recruitment email, potential participants emailed the first author and received an invitational letter and consent form via email. If the clinician wished to participate, he or she completed the consent form and emailed it to the research assistant. Consent was also confirmed verbally at the beginning of the interview. Consent information was stored separately from the interview transcripts to ensure confidentiality.

## Results

A variety of personal and environmental factors contributes to a physician's decision whether to recommend breast, cervical, and colorectal cancer screening to eligible patients, regardless of whether they have an intellectual disability. The medical environment that physicians practice within includes their geographic location and the organization of their practice, and importantly for family medicine trainees, the role of the preceptor is a key factor in whether a family medicine trainee promotes cancer screening. These factors all influence how participants provide care, including recommending cancer screening.

While care is delivered within this medical environment, situated within this medical environment is the interpersonal interaction between the physician and the patient. Factors related to this interaction are specific to each individual patient, and these factors may vary greatly from one patient to another. One factor that physicians may consider is whether a patient is vulnerable, for example, if the patient has an intellectual disability. As part of this interpersonal interaction, participants report striving to find a balance between best practice guidelines and the patient's unique needs. On the one hand they weigh the evidence-based guidelines and the patient's eligibility according to these guidelines, while they consider the benefits and potential harms of screening. Some of these harms could include distress on the part of the patient, both with coping with the screening procedures and coping with a potential diagnosis of cancer. Participants report employing their clinical judgement to decide whether the potential benefits of screening outweigh the potential risks and harms to the patient. Consequently, participants consider multiple, potentially conflicting factors while making the decision whether to recommend cancer screening to each individual patient.

In addition to weighing the potential harms and potential benefits to cancer screening for each patient, some participants also spoke of striving to give their patients autonomy in choosing their own care. They spoke of both allowing their patients to choose their care, but also relying on their patients to be proactive and seek out the care that they are eligible for.

### Applying standards of practice

One of the first considerations for physicians in choosing whether to recommend cancer screening to a patient is whether the patient meets eligibility criteria to qualify for screening. The participants in this study generally followed national guidelines for screening rather than provincial guidelines for screening, and they were also aware of the shifting evidence base and fluid guidelines for all forms of cancer screening: breast, cervical, and colorectal. Participants spoke often of considering factors such as the patient's age and gender as well as any other factors that might place that patient at higher risk for cancer prior to recommending screening.

In general, participants' accounts suggested the belief that all patients who meet eligibility criteria for screening should undergo screening. Some participants explicitly expressed the conviction that it was their role as primary care providers to recommend cancer screening to all eligible patients in their practice, regardless of the patient's abilities or background. However, several participants also acknowledged that some patients, including some patients with intellectual disability, might have additional needs that would need to be considered either in the recommendation for screening or in the screening process itself, for example, taking the time to educate a patient with intellectual disability concerning both the need for screening and the screening itself.

*Assessing eligibility for screening.* Age was the most important consideration that participants spoke of considering when recommending cancer screening. For example, many indicated that they would only recommend breast and colorectal cancer screening in patients aged 50 years and older, and cervical cancer screening in patients aged 21 years and older. Understandably, participants would consider sex for breast and cervical cancer screening. However, somewhat unexpectedly, participants did not speak of considering sex when recommending colorectal cancer screening.

Personal and family history of cancer was another factor mentioned by several of the study participants, particularly in relation to breast and colorectal cancer screening. Participants indicated they would be more likely to recommend more stringent screening procedures for patients at elevated personal or family risk of breast or colorectal cancer. For example, some participants mentioned that they would be more likely to recommend a colonoscopy as the first step in colorectal cancer screening to a patient at higher familial risk, rather than the faecal immunochemical tests (FITs) that are generally recommended for patients at average risk. As one participant explained,

> Starting at fifty, a FIT every two years, as opposed to an FOBT which is now passé, provided that they are in the . . . of average risk. If they're high risk or symptomatic, then you would consider colonoscopy more so than an FOB or an FIT.

This quote illustrates not only the differential screening modality that would be provided to a patient perceived to be at a higher risk, but also an awareness of the changing colorectal cancer screening guidelines in general.

Participants also indicated that they were familiar with the shifting evidence base for cancer screening, especially breast cancer screening, and accordingly changing recommended best practices and guidelines for screening. For example, a few participants described no longer promoting breast self-examination, as a result of guideline changes. One observation related to the shifting evidence base and evolving guidelines is that the participants were all trainees or recent graduates of medical training, thus as part of their training they may have been more aware of recent revisions and updates to cancer screening guidelines. One participant did openly wonder about whether her colleagues who are 10 or 15 years her senior would be as aware of the changing nature of cancer screening guidelines as she was. It is interesting to speculate as to whether more experienced physicians would be as likely to recommend cancer screening according to the new guidelines.

In summary, participants spoke of considering personal characteristics of the patient, such as the patient's age and sex, and also the family history and cancer risk of the patient when deciding whether to recommend a specific modality of screening. In addition, participants were aware of the shifting evidence base in relation to the guidelines and described making adjustments to their recommendations in order to accommodate these evolving guidelines. Therefore, when considering whether to recommend cancer screening to a patient, participants consider personal and family factors related to cancer risk, and place such assessment within the shifting evidence and evolving nature of cancer screening guidelines.

*Promoting cancer screening to everyone.* When asked how they provide primary care, including promoting cancer screening to their patients with intellectual disability, participants indicated that they did not consider intellectual disability as a sufficient rationale for withholding a screening recommendation. Further, many participants stated they would not differentiate during their deliberations as to whether a patient has an intellectual disability or not, and a key consideration for participants was whether the patient met screening criteria.

Many participants also indicated that they feel obligated to provide care regardless of whether an individual has an intellectual disability or not. For example, one participant explained that she provides care to everyone who ‘walks through the door’ and another said that he provides care to everyone regardless of socioeconomic status or ‘intellectual status’. One participant described her role in providing primary care to her patients with intellectual disability in the following way: ‘Doesn’t really matter that they have an intellectual disability, so just – they’re just people. You’ve just got to treat people’. This quote describes the participant’s belief in treating each patient as a whole person with multiple identities and characteristics, and not just as someone with an intellectual disability.

Some participants acknowledged that patients with intellectual disability may have additional needs or require additional accommodations during screening. For example, some participants noted that patients with intellectual disability may be accompanied by caregivers, and their viewpoints must be considered during the clinical encounter. In addition, the presence of an additional caregiver may make coordination of care more burdensome and thus more difficult to offer cancer screening. In contrast, some participants described caregivers being a valuable source of information concerning the patient’s medical history, specifically concerning whether a patient with intellectual disability is at increased risk of cancer.

Some participants also explained that patients with intellectual disability may have additional medical or social support needs that must be addressed prior to screening. Additionally, several participants discussed how prior to recommending screening, whether it is a Pap smear or FIT test, they may need to devote additional time during the medical appointment in order to explain the need and nature of screening, as some patients with intellectual disability may be initially unused to such screening or might be alarmed and not understand the preventive nature of the screening test. However, while participants acknowledged that patients with intellectual disability may have additional needs, these study participants emphasized that a patient’s intellectual disability in itself would not be an acceptable reason to withhold screening. They believed that in addition to a patient’s eligibility for screening, health providers also need to consider the needs and supports a patient may need in order for screening to be accessible.

While participants described that they would not withhold cancer screening to patients with intellectual disability on account of their disability, and while participants indicated that they would be willing to accommodate a patient with intellectual disability’s additional needs, it is important to note that the majority of participants had limited clinical experience and its associated time pressures. The majority of participants were trainee family physicians, and some participants stated they had never provided care to a patient with an intellectual disability who met the age criteria for cancer screening. Consequently, participants may have volunteered information based on hypothetical scenarios, given that most had limited actual clinical experience upon which to draw during the interviews.

In sum, participants believed that everyone eligible for cancer screening should undergo cancer screening. Participants also balanced the evidence in favour of screening with the unique needs of each patient. While participants anticipated that they would promote cancer screening to their patients with intellectual disability in a manner similar to other patients, they did recognize that some patients with intellectual disability may have additional needs that ought to be addressed prior to screening. The belief expressed by these study participants that all patients eligible for screening, including all patients with intellectual disability, should undergo screening, may also reflect their limited experience actually providing care to patients with intellectual disability.

## *Exercising clinical judgement*

Although the participants in this study were both informed and aware of evidence-based guidelines in favour of cancer screening, they also recognized that some patients, including those with intellectual disability, may have additional needs with respect to screening. While we previously described participants considering patient's personal factors and eligibility for screening, participants indicated they would also exercise their clinical judgement to tailor their care and potential cancer screening recommendation to each patient.

Many participants spoke of being aware that patients may have additional needs, including medical needs during screening and the need to make sure that all patients, including those with intellectual disability, understand the screening process. Therefore, participants would assess each patient's ability to receive screening, and develop a tailored recommendation for each patient. As one participant described, when asked how one would promote cancer screening to patients with intellectual disability:

> It depends on the severity of their intellectual disability, I think. Like, I think you'd have to take into consideration the risks versus the benefits to that specific patient. Like if a patient has to go through a general anesthetic for a particular screening, I mean, that's more of a risk – that could be more of a risk than the actual screening. So I think you have to take into consideration the level of disability.

In this quote, the participant recognizes that patients with intellectual disability may have additional needs for screening that may have inherent risks, which may lead the participant to believe the benefits of screening do not outweigh the risks for each patient, especially for patients with more severe intellectual disability. Participants also spoke of other conditions in addition to intellectual disability, for example severe anxiety, which may also cause them to evaluate whether screening, and the ability to cope with potential positive results, was in each patient's best interests. This principle that healthcare ought to be tailored to each patient's needs might result in a physician deciding that cancer screening is not in a patient's best interest, and thus not recommend screening.

In their explanations of this process of tailoring care to each patient's unique needs, participants spoke of weighing the risks and benefits prior to recommending screening. Participants were highly aware of the benefits of cancer screening, especially the benefit of early detection of cancers, and they shared a clear conviction that patients eligible for screening should undergo screening. However, participants were also aware of the distress that screening might cause for some patients. Many participants reported that they would tend to consider the patient's level of anxiety prior to recommending screening, and this might be especially the case for patients with intellectual disability. In contrast, other participants thought that, some patients might have anxiety regarding whether they had cancer, and by recommending screening, a negative test result would reassure these patients. Thus, participants spoke of weighing the risks and benefits for each patient individually and considered each patient's emotional response to both screening and potentially positive results prior to recommending screening.

In their explanations of this process of weighing the benefits of early detection with the risks of patients' anxiety in undergoing the screening procedure, some study participants speculated that physicians may be less likely to recommend cancer screening to patients with intellectual disability, believing that for this group of patients, the benefits do not outweigh the potential distress patients with intellectual disability would experience. However, participants also explained that the process of exercising clinical judgement and weighing the risks and benefits prior to recommending screening occurs for all patients, not only those with intellectual disability. This finding indicates while participants are aware of the benefits of screening, namely early detection of cancer, they also employ their clinical judgement to determine the best course of care for each patient. Thus, prior to recommending cancer screening, physicians would consider not only a patient's eligibility for screening according to guidelines, but also the patient's ability to cope with the distress and anxiety of not only the screening process itself, but also the patient's ability to cope with a potential positive result of a test.

### *Granting patients autonomy to choose their care*

Participants in this study also spoke of striving to balance a patient's eligibility for screening with a patient's ability to cope with screening and its' possible result, while at the same time attempting to respect patient's autonomy and their ability to choose which course of treatment they would prefer. One example of a patient choosing their own care was portrayed by a participant who described referring an average-risk, asymptomatic patient for a colonoscopy rather than a FIT test. While the participant indicated they would recommend a FIT test to average-risk patients, if a patient expressed a preference for a screening colonoscopy over a FIT test, the participant would likely comply with the patient's request and refer them to a colonoscopy. Other participants indicated that if a woman in her 40s, who would generally not be eligible for screening mammography, asked for a mammogram, these clinicians would still refer the patient for the test, although the patient does not meet typical screening criteria. These data exemplars illustrate how participants enable their patients to take an active role in choosing their care, even if patients choose non-recommended screening.

Rather than solely personal preference, there are other reasons why a patient, with or without an intellectual disability, might not receive cancer screening. One method that family physicians use to ensure a patient is up to date is when the patient arrives for an unrelated medical appointment. This allows the physician the opportunity to review their chart and ensure preventive care, such as cancer screening, is up to date. Similarly, some participants indicated when an older female patient attends an appointment for a Pap smear, the clinician can also promote screening mammography at this time. If a patient, for whatever reason, has little contact with their primary care provider, preventive care actions such as cancer screening may be overlooked.

However, even if a patient has regular contact with their family physician, they may still not receive cancer screenings and other preventive care. Some participants spoke of the scenario in which a physician realizes the patient is due for a cervical cancer screen, but during the appointment time there is not sufficient time to conduct the screening. The physician may ask for the patient to return for the screening, but this request depends on the ability of the patient to both book a follow-up appointment and return for an appointment. Similarly, if a woman is older and no longer attending primary care appointments for preventive care such as cervical cancer screening, the physician may not have the opportunity to promote breast and colorectal cancer screening.

Two participants also spoke of issues in relation to coordinating patients' care that may make it less likely for these patients to obtain appropriate cancer screenings, that may be more specific to patients with intellectual disability. One participant once again spoke of the added challenge of providing care to patients with intellectual disability if their caregivers are present at an appointment, because this provides an added complexity to delivering care. As was discussed by other participants when providing care to patients in general, another participant indicated that if patients do not have a regular general practitioner, cancer screening may not be promoted at regular intervals, and then this screening does not occur. Participants also suggested that both in general and specifically for patients with intellectual disability, if a regular reminder was displayed in a patient's electronic medical chart when they were due for a regular cancer screening, this would assist in facilitating a discussion regarding screening with the patient.

### *Situating the patient-physician interaction within the medical environment*

While the previous discussion has mainly been concerned with the patient-physician interaction, it is important to note that this interaction takes place within a larger medical environment. This larger environment relates to features of the physician's practice and organization of the practice, including, for trainee family physicians, the role of their preceptor in how trainee physicians deliver care. Unlike previous themes discussed thus far, the medical environment that physicians provide care within is not individualized to each patient, rather the influence of the medical environment is similar across patients.

One commonality across patient-physician interactions is the geographic location that the physician's practice is situated within. Approximately half of the participants in this study practiced in an urban or suburban setting and half practiced in a rural setting. Interestingly, when prompted, most participants reported that accessibility of cancer screening and follow-up care in their region did not impact their decision regarding whether to recommend cancer screening. For example, many clinicians practicing in rural settings described a mobile mammography clinic that served their region. Additionally, no participant that practiced in a rural setting reported that access to follow-up care for a positive test result was a concern or a hindrance to recommending cancer screening. This accessibility of care included when a patient needed a colposcopy performed by a gynaecologist or a colonoscopy performed by a surgeon or gastroenterologist.

The participants' clinical experience, both in general and specific to caring for patients with intellectual disability, also affected their responses. Most participants were trainee family physicians and described obtaining advice regarding clinical matters from the preceptor. Participants reported that their preceptor was a key influence on their provision of care: if a preceptor generally followed best practices and recommended preventive cancer screening, the trainee likely followed the same procedures. Thus, given their status as novice physicians, participants relied on guidance from more experienced physicians when anticipating how they would provide care, including promoting cancer screening.

In sum, participants' geographic location, practice constraints, and clinical experience all influence the patient-physician interaction in which cancer screening is promoted. These factors were clearly seen by these participants to influence how they thought they would promote cancer screening to patients with intellectual disability as part of routine practice. In addition, while most of the factors influencing a cancer screening recommendation where specific to the patient-provider interaction, the influence of the medical environment has less variation across patients.

Promoting cancer screening as part of a primary care practice is complex and becomes even more complex when a patient has additional needs due to an intellectual disability or other condition. Participants in this study clearly believed that everyone eligible for cancer screening should receive such screening. However, participants did note that it may be more complex for their patients with intellectual disability to access such cancer screening, as more accommodation during the medical appointment and consultation with the patient's caregivers might be needed. Further, participants also wish to give their patients the ability to exert some choice within their care while ensuring that patients are supported to receive all of the screening for which they are eligible. All of these considerations play out in the larger backdrop of the medical environment in which they provide care, and this environment may feature in how each clinician delivers care over time, including recommending cancer screening.

## Discussion

Two key findings emerged from this study. First, it appears that primary care providers consider a patient's intellectual disability to be one of a multitude of factors influencing a cancer screening recommendation. Clinicians stated they feel they provide a similar level of care to all patients, and they also feel that having an intellectual disability is an unacceptable reason to withhold preventive care such of cancer screening, even if it necessitates additional commitment on their part. Rather, clinicians also stated they consider multiple characteristics, including but not limited to an intellectual disability, prior to deciding whether to recommend cancer screening. Second, family physicians also indicated that they are generally aware that national guidelines for cancer screenings are in a state of flux, and that the evidence supporting each modality of screening is currently shifting as new evidence becomes available. For example, clinicians in the present study were aware that Canadian guidelines advise against screening mammography in women under 50 years of age and cervical cancer screening in women under 21 years of age. Participants in this study indicated they apply the same guidelines to all of their patients, while at also considering the need to individualize care to each patient.

### *Family physicians' knowledge of, and application of, evidence-based cancer screening guidelines*

The authors did not set up to examine primary care providers' adherence to general cancer screening guidelines. However, during the interviews, it emerged that physicians are aware of both the shifting evidence base for all three forms of cancer screening (breast, cervical, and colorectal) and consequently the evolving nature of current cancer screening guidelines, in particular in the national setting. It is possible that because the majority of the physicians in this study were recent graduates, as part of their medical education they were more aware of the evolving nature of current cancer screening guidelines.

At the time of data collection, the cancer agency in the province the study was conducted had differences in recommended age for breast and cervical cancer screening relative to national guidelines. For example, until 2016 this agency had specified no minimum age for cervical cancer screening, unlike the national guidelines, which set a minimum age of 21 years. We had expected that because health is a provincial jurisdiction in Canada, physicians would be more familiar with provincial screening guidelines, as this would be relevant to their compensation for services. However, participants indicated that family physicians were generally more knowledgeable regarding the Canadian Task Force on Preventive Health Care (CTFPHC, 2011, 2013) guidelines, and were less familiar with the provincial agency guidelines. For example, because participants applied the CTFPHC guidelines, they were reluctant to recommend cervical cancer screening guidelines to women under the age of 21 years. (Since the qualitative phase data collection for this study was conducted, the provincial agency has introduced a minimum age of

25 for cervical cancer screening). Participants also indicated that they would be hesitant to refer a woman for a screening mammogram if she was between the ages of 40 years and 50 years. While the provincial guidelines have recently been changed to no longer encourage screening mammography for average risk women under 50 years of age, the CTFPHC guidelines have advised against screening in women under 50 years of age for several years. Thus, in it appears that although health is a provincial responsibility in Canada, physicians were more aware of national guidelines for screening.

Related to this finding, and one that has not been explored in previous research on the effect of attitudes in screening decisions, is that participants realized that the evidence in favour of screening mammography, even for women over the age of 50, was being questioned in the published medical research. However, given that screening guidelines by government bodies had not changed, participants indicated that they continued to recommend screening mammography to women over the age of 50 years. Therefore, because, at the time of writing, screening mammography recommendations for women over the age of 50 years had not changed in Canada, participants anticipated recommending screening for patients in this age group.

Thus, it appears that, while participants are aware of the recent publication of studies questioning the value of comprehensive screening mammography programmes, they do not change their clinical practice unless published guidelines and established standards change. To date, there has been limited research exploring how primary care providers employ cancer screening guidelines. Guidelines for all forms of cancer have changed in recent years, and participants appear to be aware of both current national screening recommendations, and the shifting evidence base in favour of such screening. In addition, unlike oncology specialists, family physicians may consider their work as taking place outside of the provincial cancer care structures, which may have led to them being more familiar with the national screening guidelines rather than the provincial guidelines.

### *Family physicians accommodating patients with intellectual disability's needs with regards to cancer screening*

Participants indicated that they are aware of the need for screening in individuals with intellectual disability, and that they would accommodate patients with intellectual disability needs with regards to screening. Specifically, participants indicated they would accommodate patients with intellectual disability's needs, even if this led to increased time pressure on the part of physicians. This may reflect participants' limited clinical experience, both with providing care to individuals with intellectual disability, and their limited experience working in a clinical setting with multiple time pressures. It is also possible that the participants had pre-existing positive attitudes towards people with intellectual disability, and this led to participants anticipating that they would be able to accommodate patients with intellectual disability's needs with regards to screening.

Previous research has indicated that medical staff working with people with intellectual disability report having a lack of information on how to support their patients in accessing screening. However, health professionals felt they had sufficient knowledge regarding screening in the general population (Hanna et al., 2011; Kirby and Hegarty, 2010; McIlfatrick et al., 2011; Tyler et al., 2010). Self-advocates (women with intellectual disability; Parish et al., 2012; Truesdale-Kennedy et al., 2011; Wilkinson et al., 2011) also reported that they lacked information regarding cancer screening, both the need for screening and the nature of screening itself. A more recent systematic review (Byrnes et al., 2020) also suggests that education for all individuals involved in cancer screening, including family physicians, can facilitate training. The present study's finding, that participants felt they would promote cancer screening to their patients with intellectual disability, even if it required additional time in the clinical interaction in order to accommodate their patient's needs, is in contrast to previous findings. Alternatively, it is also important to consider the participants in the present study had limited experience providing care to this population. Given that many participants reported never being in the clinical scenario in which they were providing care to an adult with intellectual disability who was eligible for screening, it is possible they were minimizing the additional time required within a clinical encounter to promote the screening.

A final consideration regarding how participants provide care in a general sense to individuals with intellectual disability as well as in relation to such practices as cancer screening is that they appear not to believe that there are – or ought to be – specific protocols or practices mandated for providing care to such patients. Rather, the findings of this study indicate that participants weigh the risks and benefits for screening for each patient, including whether patients might have additional needs due to an intellectual disability.

Previous research recommends certain steps or practices that health professionals can adopt to provide more inclusive care to patients with intellectual disability. For example, Baumbusch et al. (2014) and Wullink et al. (2009) interviewed individuals with intellectual disability, and found that participants described certain styles of patient-physician communication that they find helpful in clinical encounters. Similarly, Wilkinson et al. (2013) interviewed both patients with intellectual disability and physicians and found that participants described certain aspects of patient-physician communication which were preferred. For example, in many of the studies, individuals with intellectual disability expressed a desire for physicians to provide medical information in plain language, without using complex medical jargon. These studies concluded that adults with intellectual disability wish to receive care in a manner similar to other patients. In contrast, the current study appears to indicate that clinicians do not believe there is a one-size-fits-all approach to providing care to patients with intellectual disability, and they will then deliver individualized care to each patient. This finding suggests there may be a discrepancy in the care that patients with intellectual disability wish to receive, and their care providers' perceptions of how to provision care.

Thus, the motivation of these clinicians to individualize care may reflect their positive attitudes towards of people with intellectual disability. Participants would provide care and promote cancer screening in a similar manner for all patients, perhaps not realizing the nuances of providing care to patients with intellectual disability. Their lack of clinical experience, both with this patient population and in the clinical environment, with its associated time pressures, may have also influenced their results. While this study's participants may have had more positive attitudes towards people with intellectual disability, they may have also had less experience providing preventive care to this population.

## Limitations

While the majority of participants in the quantitative phase of our wider study were highly experienced, the majority of interviews in the qualitative phase were conducted with trainee family physicians who had relatively little clinical experience. This was mainly due to recruitment challenges, and the study would have been more rigorous if we had been able to recruit more experienced clinicians into the interview portion of the study. Because qualitative phase participants were generally family medicine trainees, they had less clinical experience providing care to patients with intellectual disability; thus, the data generated in this phase may not be as rich as if more experienced clinicians had taken part.

### Future research

Given that the majority of participants in this study were family medicine trainees, and had limited clinical experience at the time, future research could seek to recruit more experienced physicians. This is because physicians with more experience providing care to adults with intellectual disability who are eligible for cancer screening may report different experiences. More broadly, more research is needed to explore how primary care providers, in particular family physicians, provide care to their patients with intellectual disability in the clinical setting, including providing health promotion and disease prevention behaviours.

## Conclusion

The findings of this study suggest that family medicine physicians and trainees whose attitudes towards intellectual disability are reasonably favourable will recommend breast, cervical, and colorectal cancer screening to their patients with intellectual disability. Physicians consider both evidence-based guidelines and the patient's best interests prior to recommending screening, while at the same time considering patients' autonomy and right to choose treatment. This decision-making process occurs within the complex medical environment within which the physician practices. More research is needed to better understand how experienced family physicians recommend disease prevention measures, such as cancer screening, as part of routine care.

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### Author contributions

GB conducted this research as part of her doctoral dissertation. ST and JB were her primary supervisors, and TGH and AK were doctoral committee members, and thus provided supervision and support in all phases of the research. All authors read and approved the final manuscript and final author order.

### Data availability statement

The datasets analysed during the current study are available from the corresponding author on reasonable request.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Ethical approval

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