

PRIMARY CARE PROVIDERS' ATTITUDES AND EXPERIENCES RECOMMENDING
CANCER SCREENING TO PATIENTS WITH INTELLECTUAL DISABILITIES

by

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Abstract

Individuals with Intellectual Disabilities receive breast, cervical, and colorectal cancer screening at rates lower than the general population. The reasons for this disparity are poorly understood. Additionally, in the general population, a primary care provider's recommendation for cancer screening is one of the key determinants of whether an individual obtains cancer screening. This mixed methods study explored the role of primary care providers in recommending cancer screening to patients with Intellectual Disabilities. First, 106 primary care providers (family physicians, family medicine residents, and nurse practitioner students from across British Columbia) were surveyed regarding their attitudes towards people with Intellectual Disabilities in general, and their anticipated likelihood of recommending breast, cervical, and colorectal cancer screening to fictional patients with Intellectual Disabilities presented in vignettes. In the second phase, 10 family medicine residents and two family physicians were interviewed regarding their experiences recommending cancer screening to patients with Intellectual Disabilities. The quantitative and qualitative analysis revealed that: (1) participants with negative attitudes towards the community inclusion of individuals with Intellectual Disabilities were less likely to recommend breast and colorectal cancer screening to fictional patients with Intellectual Disabilities; and (2) participants balance applying evidence-based guidelines with exercising clinical judgement to determine the best course of care for each patient, and this balance is situated within the larger medical environment that physicians practice within. In conclusion, this study determined that aspects of attitudes are related to cancer screening recommendations, but given that attitudes are one of many factors related to screening recommendations, future studies should not solely focus on this factor. Second, it appears that clinicians individualize care for all patients, and a patient's Intellectual Disability is one of many

factors considered prior to a screening recommendation. Finally, participants were aware of the evolving nature of cancer screening guidelines, and changed their practice accordingly as guidelines change. More research is needed to determine if these findings are applicable to more experienced primary care providers, given that the majority of participants in the interview phase were residents.

Preface

This dissertation is based on an original research idea by Genevieve Breau. The data collection for the quantitative phase was conducted by Genevieve Breau. The data collection for the qualitative phase was conducted by Genevieve Breau, with Hanneke Croxen, RN, MSN, research assistant, conducting the majority of the interviews. The data analysis for both phases was conducted by Genevieve Breau. To date, no published journal articles have resulted from this work.

This research project received ethical approval from the University of British Columbia Behavioural Research Ethics Board, and was also reviewed by the University of Victoria Research Ethics Board. The title of the ethics application is: “Primary Care Providers’ Attitudes and Experiences Concerning Recommending Cancer Screening to Individuals with Intellectual Disabilities,” and the ethics certificate number is H14-03029. This research also received approval from the University of British Columbia School of Nursing, the University of British Columbia Faculty of Medicine Research Access Committee, and the University of Northern British Columbia Provost’s Office.

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Dedication

This dissertation is dedicated to my parents, Pierre and Lynn Breau. Their love and support have helped me throughout my life. I could not have written this dissertation without them. Thank you Mom and Dad!

CHAPTER 1: Introduction

Cancer screening improves cancer outcomes through early detection. Research suggests that women with Intellectual Disabilities may not receive screening for breast or cervical cancer at rates comparable to the general population, and individuals with Intellectual Disabilities also face disparities in obtaining colorectal cancer screening. For example, a study in Ontario found that women with Intellectual Disabilities were less likely to have had a Pap test in the previous three years (adjusted OR =0.21, 95% CI 0.20-0.21) and women with Intellectual Disabilities aged 50-69 were less likely to have received a mammogram in the previous two years (adjusted OR = 0.46, 95% CI 0.43-0.49) (Cobigo et al., 2013). Another recent Ontario study also found that individuals with Intellectual Disabilities were less likely to have received a fecal occult blood test to screen for colorectal cancer in the previous two years (adjusted OR=0.68, 95% CI 0.65-0.71, Ouellette-Kuntz, Coo, Cobigo, & Wilton, 2005) relative to members of the general population. Studies such as these raise the possibility that those with Intellectual Disabilities may face poorer outcomes, because lower screening rates lead to their cancer being detected at later stages.

This dissertation describes a study aimed at exploring the role of primary healthcare providers in recommending breast, cervical, and colorectal cancer screening to individuals with Intellectual Disabilities. A sequential, convergent mixed-methods design was used (Creswell & Plano Clark, 2011) to explore potential factors related to respondents' decision to recommend cancer screening. This research was conducted in two phases. First, a cross-sectional survey explored the contribution of primary care providers' attitudes towards people with Intellectual Disabilities to their recommendation of cancer screening. Second, open-ended interviews were completed to further explain the survey findings within the broader clinical decision-making

context and to explore other possible factors that may relate to the primary care decision to recommend or not recommend cancer screening to people with Intellectual Disabilities. In addressing this research question, however, it is important to understand that individuals with Intellectual Disabilities are affected by breast, cervical, and colorectal cancer.

Cancer Incidence in the General Population and in Individuals with Intellectual Disabilities

Breast, cervical and colorectal cancers are relatively common among Canadians. In 2016, the most recent year for which data are available, breast cancer was the most common form of cancer among Canadian women. That year, an estimated 130.1 per 100,000 new cases of breast cancer were diagnosed (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2016). That same year, there were an estimated 79.5 per 100,000 new cases of colorectal cancer among Canadian men and 54.5 per 100,000 new cases among Canadian women. In contrast, cervical cancer is relatively rarer, with an estimated 8.0 per 100,000 new cases among Canadian women in 2016. This may be due to comprehensive cervical cancer screening programs targeting the general population.

Unfortunately, the Canadian Cancer Society does not report on the incidence or mortality of cancer specifically among individuals with Intellectual Disabilities. Two studies, however, did examine cancer incidence in people with Intellectual Disabilities outside of Canada. Patja, Eero, and Iivanaienen (2001) report that women with Intellectual Disabilities in Finland are diagnosed with breast cancer at a rate similar to the general population, and individuals with Intellectual Disabilities have an incidence of colorectal cancer that is also comparable to the general population (Patja et al.). In contrast, Patja et al. found that women with Intellectual Disabilities have a lower incidence of cervical cancer and suggest one reason for this may be that many of the women in their cohort would have been institutionalized, meaning that they may have been

less likely to be sexually active, a known risk factor for cervical cancer (National Cancer Institute, 2015). Sullivan et al. report that Australian women with Intellectual Disabilities have a lower incidence of breast cancer, relative to the general population, and suggest their finding could be due to women with Intellectual Disabilities having had a lower screening mammography rate (Sullivan, Hussain, Threlfall, & Bittles, 2004). That group also report that, while men with Intellectual Disabilities have an incidence of colorectal cancer similar to the general population, women with Intellectual Disabilities have a significantly higher rate of colorectal cancer. Because a high fat diet is a risk factor for colorectal cancer, the authors posit that the greater likelihood of this risk factor among women with Intellectual Disabilities may account for the higher rate of colorectal cancer observed among them. Thus, as with cervical cancer, lifestyle factors may be one contributor to colorectal cancer rates among individuals with Intellectual Disabilities.

It is important to keep in mind that risk factors may change within a population. Given the shift away from institutionalization and towards community inclusion (Henry, Keys, Jopp, Balcazar, 1996), it is possible that, as Patja et al. (2001) suggest, younger women with Intellectual Disabilities who live in the community are now more likely to be sexually active, which increases their risk for cervical cancer relative to their older peers. There is also no research examining whether incidence rates of cervical cancer have changed among women with Intellectual Disabilities since the Patja et al. study was conducted in 2001. Therefore, although de-institutionalization may play a role, its specific impact on cervical cancer rates in this group is yet unconfirmed. Importantly, other factors, in addition to type of residence, influence sexual activity and may also contribute to cervical cancer incidence.

Other lifestyle factors are also not necessarily static. Diet may also change over time, whether due to living situation changes or to trends in society as a whole. Life expectancy has also changed over the past few decades for countries in the developed world, and a key risk factor in breast and colorectal cancer is age (BCCA, 2016), with older individuals being more likely to be diagnosed with these types of cancer. The life expectancy for individuals with Intellectual Disabilities is also increasing, with individuals with mild levels of Intellectual Disabilities having a life expectancy similar to the general population (Bittles et al., 2002). Increasing numbers of individuals with Intellectual Disabilities are surviving into their sixties and seventies, the age in which individuals are at greater risk of developing breast and colorectal cancers (BCCA, 2016). Thus, increased longevity may also contribute to breast and colorectal cancer rates among individuals with Intellectual Disabilities.

In summary, the little information available at this time suggests that those with Intellectual Disabilities have comparable, or greater, risk for breast, cervical and colorectal cancer than the general population. There is also a possibility that risk for some cancers may increase for younger cohorts, because a move to inclusion within society may be exposing them to risk factors that were partially lessened when previous generations of those with Intellectual Disabilities were routinely institutionalized. Further, longer life expectancy may also be increasing risk for some cancers for older individuals with Intellectual Disabilities. This potential of increasing risk, in addition to documented disparities, heightens the urgency of determining whether there are factors that impact their receipt of cancer screening.

Cancer Screening Recommendations

Breast, cervical, and colorectal cancers are all treatable if they are detected early through screening (BCCA, 2016). It is important to note that, in spite of some recent evidence

questioning the effectiveness of breast cancer screening, all forms of cancer screening are recommended by the British Columbia Cancer Agency (BCCA). Cancer screening detects cancers at earlier stages (BCCA, 2016) and is recommended because cancer is prevalent in the general population (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Thus, although guidelines and recommendations may evolve in the future, presently major cancer organizations believe there is a benefit to screening for breast, cervical and colorectal cancer.

The different types of screening, the eligibility for each type of screening, and the evidence in favour of each type of screening, are discussed in more detail in the Chapter 2. There is no research indicating those with Intellectual Disabilities are at less risk for breast, cervical or colorectal cancer and some research suggests that they may have a higher rate of some risk factors (Sullivan et al., 2004; Bittles et al., 2002). Thus, individuals with Intellectual Disabilities in British Columbia who are at average risk for these cancers should receive screening according to BCCA guidelines. Despite this, studies in another Canadian province indicate this may not be the case (Cobigo et al., 2013; Ouellette-Kuntz et al., 2015). One potential reason for the reduced cancer screening rates for individuals with Intellectual Disabilities could be that primary care providers are less likely to recommend cancer screening to people with Intellectual Disabilities.

Healthcare Providers' Attitudes Regarding Individuals with Intellectual Disabilities

There are only a small number of studies examining the possible role of healthcare providers' attitudes towards this population in their decision to recommend cancer screening. For example, family members of women with Intellectual Disabilities reported that healthcare professionals frequently told them that their relatives did not need cervical cancer screening (Swaine, Dababnah, Parish, & Luken, 2013). In addition, Llewellyn, Balandin, Poulos, and

McCarthy (2011) report that women with physical and Intellectual Disabilities indicated that healthcare providers told them that screening mammography was not necessary for women with disabilities like themselves. Although there are no studies examining primary care providers' recommendation rates for colorectal cancer screening in individuals with Intellectual Disabilities, it is possible that a similar tendency by primary care providers is one factor influencing those screening rates as well.

The recommendations of the providers in these studies were not necessarily consistent with commonly accepted guidelines. Thus, the results suggest the possibility that factors other than clinical evidence or screening guidelines may be influencing whether or not primary care providers recommend cancer screening to these individuals. There is a possibility that primary care providers' attitudes about people with Intellectual Disabilities are one factor. This hypothesis corresponds to Ajzen's (1991) Theory of Planned Behaviour. In this model, Ajzen considers attitudes to be a predictor of whether an individual performs a behaviour. A recent study found his Theory of Planned Behaviour was useful in conceptualizing health professionals' clinical behaviour (Breau, 2014), suggesting that health professionals' attitudes towards individuals with Intellectual Disabilities could also be influencing whether they recommend cancer screening to their patients with Intellectual Disabilities.

This possibility is supported by the fact that researchers have found that some subgroups of healthcare providers have negative attitudes towards individuals with Intellectual Disabilities or lack knowledge regarding care for them. Nurses have reported negative attitudes about people with Intellectual Disabilities (Matziou et al., 2009) and family physicians have also reported that they lack Intellectual Disabilities-specific training (Wilkinson, Dreyfus, Bowen, & Bokhour, 2012). In contrast, others have shown that these attitudes and lack of experience may be

overcome with training. For example, Sanders et al. (2007) developed two virtual patient modules with pediatric patients with Intellectual Disabilities, and found that after completing the modules, nursing students reported significantly higher knowledge and comfort in caring for patients with Intellectual Disabilities. More specific to recommendation for cancer screening, nurses' attitudes have been found to be related to whether they recommend other forms of preventive care, such as offering smoking cessation advice (Puffer & Rashidian, 2004). In summary, although no study to date has examined whether healthcare providers' attitudes are related to clinical behaviour in relation to cancer screening, relevant literature suggests it is very possible that they do, making it important to understand what their attitudes are, how they impact the decision making process, and ultimately, healthcare providers' actions in relation to this vulnerable population. It was hoped that this study would be one step towards improving our understanding.

Aim of this Study

The aim of this study was to increase our understanding of the factors related to primary care providers' recommendation of cancer screening to individuals with Intellectual Disabilities. Breast, cervical, and colorectal cancer screening were all considered, because currently the BCCA (2016) recommends all three types of screening for residents of British Columbia. Inclusion of multiple forms of cancer screening also allowed for comparisons between types of cancer screening so that the results would be relevant to more than one type of cancer screening and to both genders. The cross-sectional survey portion of this study focused on whether one factor, the attitudes that primary care providers (family physicians) and primary care provider students (nurse practitioner students and family practice residents) have regarding individuals with Intellectual Disabilities were related to whether the participants anticipated recommending

cancer screening to hypothetical patients with Intellectual Disabilities presented in written vignettes. This was followed by exploratory, descriptive interviews with family physicians and family practice residents to further explore the role of attitudes, as well as to investigate other possible factors that may influence their decisions to recommend or not recommend screening to their patients with Intellectual Disabilities.

The Theory of Planned Behaviour and its Contribution to the Study

Because healthcare professionals' recommendation for cancer screening is a key factor determining whether individuals obtain cancer screening (Coughlin, Breslau, Thompson, & Benard, 2005), it was assumed that asking primary care providers concerning the likelihood of recommending screening served as a reasonable proxy for actual screening. This assumption was based on Ajzen's (1991) Theory of Planned Behaviour, which posits that an individual's intention to perform a behaviour, in this case recommending cancer screening, is related to whether the actual behaviour occurs. This means that asking participants about their anticipated likelihood of recommending cancer screening to patients with Intellectual Disabilities was an effective measure of whether actual screening recommendations would be given. It was believed that this mixed-methods approach, with an initial survey phase, would provide a good first step to better understanding this phenomenon.

Overview of the Dissertation

Chapter 2 describes the recommendations and guidelines for breast, cervical, and colorectal cancer screening in the general population. Evidence in favour of each type of screening is also reviewed. The goal of this chapter is to review the evidence for why cancer screening should occur.

Chapter 3 follows with a discussion of the disparities in cancer screening experienced by members of the general population, and Chapter 4 describes the disparities in cancer screening experienced by individuals with disabilities, including Intellectual Disabilities. These chapters outline the degree of disparity experienced by these groups, and qualitative research exploring the possible reasons for these disparities among individuals with disabilities is examined. One of the possible reasons for the disparities experienced by individuals with disabilities, negative attitudes about individuals with Intellectual Disabilities, is explored in Chapter 5.

In Chapter 6 the methods used in this explanatory mixed-methods design are reviewed in detail. In Chapter 7, I present the findings of the survey phase, while in Chapter 8, I present the qualitative findings. Finally, in Chapter 9, I discuss how these two phases relate to each other, and then to the previously published research. I then discuss the research and clinical implications of the results found.

Chapter 1 Summary

By better understanding the factors related to primary care providers' recommendation for cancer screening among individuals with Intellectual Disabilities, suggestions for changes to practice are possible. People with Intellectual Disabilities obtain breast, cervical, and colorectal cancer screening at rates lower than the general population. This is problematic, because cancer screening is effective in producing better cancer outcomes for patients. One factor believed to contribute to these rates is primary care providers' attitudes towards people with Intellectual Disabilities, which is explored in the survey phase of the present study. The survey phase explores whether negative attitudes contribute to lower rates of primary care providers recommending cancer screening, a factor shown to be related to patients obtaining screening. The qualitative results help place the survey results into context, and explore primary care

providers' decision to recommend or not recommend cancer screening to patients with Intellectual Disabilities.

CHAPTER 2: Evidence for and Current Recommendations regarding Breast, Cervical and Colorectal Cancer Screening

Breast, cervical, and colorectal cancer screening is recommended by many organizations and government bodies, including the British Columbia Cancer Agency (BCCA), although the age range, modality, and interval between screenings may vary by geographic location and screening type. Many organizations have developed guidelines or recommendations for cancer screening. For example, the BCCA issues guidelines that clinicians must follow, to establish eligibility for publically-funded screening. In contrast, federal governments, professional organizations, and non-profit organizations frequently issue recommendations indicating who should receive screening, but these are less binding.

It is important to note that cancer screening guidelines and recommendations apply to the general public. Those with a family or personal history of cancer may require specialized screening due to their increased risk for cancer. However, all guidelines should be applied to individuals with Intellectual Disabilities at average risk for developing cancer, because there is no evidence indicating that having an Intellectual Disability should influence whether cancer screening is recommended.

For this study the BCCA guidelines were followed. This was because the study took place in British Columbia (BC), and the BCCA guidelines outline the screenings that the BC medical plan will support financially. It was also expected that most primary healthcare providers would be most aware of these local guidelines and most likely to use them in making care decisions. Throughout the chapter, the cancer screening guidelines developed by the British

Columbia Cancer Agency (BCCA, 2016) are described. Recommendations by other organizations in Canada, the United States, the United Kingdom, and Australia, and of other Canadian bodies are then reviewed. It is expected that clinicians practicing in BC would be aware of Canadian guidelines. American recommendations are also included, because healthcare professionals in Canada may also be aware of these. Guidelines from the United Kingdom (UK) and Australia are also reviewed, because both countries have publically funded healthcare systems similar to Canada, and because many studies examining health disparities for people with Intellectual Disabilities, reviewed in subsequent sections of this dissertation, were conducted in these countries. There are also multiple methods of screening for each type of cancer being discussed. The evidence supporting each method is also described.

Breast Cancer Screening

There are three methods of screening for breast cancer: breast self-examinations, clinical breast examinations, and screening mammograms. Breast self-examinations involve a woman palpating her own breasts to check for lumps. Clinical breast examinations involve a healthcare provider palpating a woman's breasts to check for lumps. Screening mammograms involve a technician taking a radiographic image of a woman's breasts in order to detect lumps too small to be detected manually. Screening mammography has different intentions relative to diagnostic mammography. Screening mammography is used to detect early stage breast cancer in asymptomatic women (BCCA, 2016), while diagnostic mammography is used to evaluate breast cancer in women who seek medical attention for lumps detected either manually or through screening mammography. In this section, the guidelines and evidence for breast self-examination, clinical breast examinations, and screening mammography will be reviewed.

Guidelines for diagnostic mammography will not be reviewed, because diagnostic mammography is related to cancer treatment and not preventive care.

During the 1990's, breast self-examinations, clinical breast examinations, and screening mammography were recommended by organizations in Canada and elsewhere. Starting in the 2000's, many health organizations no longer recommended breast self- or clinical examinations, or recommended caution with using these forms of screening, based on researchers' questions regarding their effectiveness. More recently, some researchers, such as Miller et al. (2014), have questioned whether the benefits of screening mammography outweigh the harms. No government bodies or non-profit organizations have yet revised their recommendations for screening mammography, primarily because they consider the benefits to outweigh the harms. However, many do suggest that women be informed of the potential harms of screening mammography when deciding whether to be screened. The primary harm of concern is over-diagnosis, in which a non-malignant tumour is treated aggressively and unnecessarily (Welch, 2009). In contrast, most organizations no longer recommend breast self-examination and manual examinations by healthcare providers, positing that the benefits of these types of screening do not outweigh the harms.

Breast self-examinations and clinical breast examinations recommendations.

Currently, as an alternative to breast self-examinations, Cancer Care Ontario (2015a), the American College of Obstetricians and Gynecologists (2011) and the UK National Health Service (NHS) Breast Screening Programme (2015a) recommend that women be "breast aware"; noting and reporting changes in their breasts, while not recommending formal, routine self-examinations. In contrast, the British Columbia Cancer Agency (2016), the Canadian Task Force for Preventive Health Care (2011), and the United States Preventive Services Task Force (2009)

recommend against all forms of breast self-examinations, including being breast aware. These organizations argue that the harms of over-treatment of benign lumps outweigh the benefits of early detection.

An emerging literature supports the growing trend not to recommend clinical breast examinations. Baxter (2001), as part of the Canadian Task Force on Preventive Health Care, first recommended against teaching breast self-examinations due to a lack of evidence of benefit and much evidence of harm, primarily consisting of unnecessary follow-up tests. Supporting this recommendation, in 2009, the United States Preventive Services Task Force updated their 2002 systematic review on breast cancer screening, and found that there was insufficient evidence to continue recommending breast self-examinations. In 2011, the Canadian Task Force on Preventive Health Care (2011) came to similar conclusions, in that they found insufficient evidence to continue to recommend breast self-examinations and clinical breast examinations. Thus, in line with the emerging research, and with the exception of the American College of Obstetricians and Gynecologists (2011), most organizations currently recommend against conducting clinical breast exams. Of note, Cancer Care Ontario (2015a) and the NHS Breast Screening Programme (2015a) do not explicitly discuss whether women should undergo clinical breast examinations. Thus, at this time, most organizations who weigh in on the issue recommend against clinical breast examinations as a routine screening practice.

Screening mammography recommendations.

Although guidelines recommending its implementation vary, most health organizations continue to recommend screening mammography. The British Columbia Cancer Agency (BCCA), Breast Screen Australia, the Canadian Task Force on Preventive Health Care (CTFPHC), Cancer Care Ontario (CCO), and the United States Preventive Services Task Force

(USPSTF) recommend that women in their stated eligible age range attend screening mammography once every two years (BCCA, 2014; Breast Screen Australia, 2015; CTFPHC, 2011; CCO, 2015a; USPSTF, 2009). The American College of Obstetricians and Gynecologists (ACOG, 2011) recommends screening mammography annually, and the UK NHS Breast Screening Programme (2015a) recommends a three year interval. Thus, within their eligible age ranges, recommendations vary from yearly to every three years.

As with recommendations for the frequency of mammography, recommendations also vary regarding recommended age for screening, although most recommend it for women aged 50 years and older, up to age 74 years. The Canadian Task Force on Preventive Health Care (2011), the United States Preventive Services Task Force (2009) and Cancer Care Ontario (2015a) recommend screening mammograms for women aged 50-74 years, but recommend against women aged 40-49 years obtaining mammograms. Similarly, BreastScreen Australia (2015) recommends screening mammography only for women aged 50-69 years. Although prior to 2014, the British Columbia Cancer Agency (BCCA) recommended annual screening mammograms for women aged 40-49, it now recommends against screening mammography in this age group. Only the American College of Obstetricians and Gynecologists (2011) continues to recommend screening mammography for women aged 40-49 years.

In contrast to the multiple organizations recommending against screening mammography in women aged 40-49 years, in 2014 the UK NHS Breast Screening Programme (2015a) began expanding the eligible age range to include women aged 47 to 73 years. The expansion is still ongoing at the time of writing. Therefore, while the recommended age range for mammography has decreased in the U.S. and Canada, it is increasing in the U.K. Despite the fact that screening mammography is shifting downward in the UK, most North American organizations have

concluded that the harms of screening mammography outweigh the benefits in women aged 40-49 years.

The differences in the recommended age ranges for screening mammography guidelines reflect emerging research regarding the benefits and harms for women under age 50 years. In 2001, the Canadian Task Force on Preventive Health Care (CTFPHC) found there was mixed evidence in favour of screening mammography for this age group. The CTFPHC reports that, while screening mammography detected more cancers in this age group relative to clinical breast examinations, the false positive rate was higher than for older women. The task force recommends that women aged 40 and older be informed of the benefits and harms of screening mammography prior to screening, and to allow women themselves to make the decision as to whether to be screened.

In 2009, the United States Preventive Services Task Force (USPSTF) updated their 2002 systematic review to evaluate whether women aged 40-49 years should receive screening mammograms. The USPSTF concluded that the 39-49 year-old participants of eight clinical trials who received screening had a pooled relative risk for breast cancer mortality of 0.85 (95% CI 0.75-0.96). The reduction in breast cancer mortality among women aged 39-49 years who had received screening mammography was similar to that found for six clinical trials of screening mammography including women aged 50-69 years (RR=0.86, 95% CI 0.75-0.99). Interestingly, in spite of this result, the USPSTF 2009 guidelines continue to recommend against screening mammography in women under 50 years of age.

In 2011, the Canadian Task Force on Preventive Health Care (CTFPHC) reached similar conclusions concerning screening mammography in women under the age of 50, although they

report a smaller absolute benefit for women under the age of 50 than the USPSTF. The CTFPHC estimated that for every million women aged 40-49 years screened, 474 breast cancer deaths were prevented, compared to 1,387 deaths from breast cancer for every million women screened who were aged 50-69 years. They concluded that screening mammography is less effective at preventing breast cancer related deaths in younger women. Unlike the USPSTF, however, they do not recommend against screening in women under the age of 50, but do recommend that women in the eligible age range should be informed of the risks.

More recently, additional evidence has suggested that the reason women aged 40-49 years do not derive the same benefit from regular screening mammography as those who are older is because their greater likelihood of having dense breasts makes it more difficult for radiologists to identify early stage breast cancer. This phenomenon results in more false positives (CTFPHC, 2011).

In summary, most organizations now recommend against screening mammography in the 40-49 age group. The rationale is that it appears screening in women aged 40-49 years prevents fewer breast cancer related deaths, and this group of women experience more false positive results relative to older age groups. However, most organizations do recommend screening mammography for women aged 50-69 years or older. Screening in this age group is thought to prevent more breast cancer related deaths relative to younger women, and the benefits of screening mammography appear to outweigh the harm in this older group.

Evidence for screening mammography.

Within the growing body of research examining whether screening mammograms should be recommended, more recent studies have begun to question whether the benefits of screening

mammography outweigh the harms even in women aged 50 years or older. As with screening in younger women, the main benefits are early detection and preventing breast-cancer related deaths, while the main harms are false positive results resulting in over-diagnosis and over-treatment of benign tumours.

One recent Swedish study found positive results for screening mammography. A 29 year follow-up of the Swedish Two County Trial in women aged 40-74 years found a 27% reduction in breast cancer mortality in the screening group (RR=0.73, 95% CI 0.59-0.82) (Tabar et al., 2011). Nonetheless, other studies and systematic reviews have questioned whether breast cancer mortality is significantly reduced, and whether screening mammography, even in women aged 50 years and older, is beneficial. In 2011, Gotzsche and Nielsen (2011) published an update of their 2009 Cochrane review. Unfortunately Tabar et al.'s (2011) study was not published in time to be part of their report. They reached similar conclusions in their 2011 review as in their 2009 review; that the benefit of early detection and the associated reduction in mortality with mammography outweighed the potential harm of over-diagnosis and over-treatment. A subsequent 2013 update by the same authors identified eight clinical trials, excluding one study that did not have comparable experimental and control groups. When considering this new group of studies, Gotzsche and Nielsen found the overall relative risk of breast cancer mortality after 13 years for all seven trials was significant (RR=0.81, 95% CI 0.74-0.87). It is important, however, to examine the types of studies they found, as this did impact their results. The relative risk for the four trials with inadequate randomization was significant (RR=0.75, 95% CI 0.67-0.83). In contrast, in the three trials with adequate randomization, the reduction in breast cancer mortality in the screened group was not significant (RR=0.90, 95% CI 0.79-1.02), indicating no net benefit to screening. Thus, the subset of evidence based on the more rigorously designed trials did not

support screening mammography. Taking these new data into consideration, and also considering that many of the women in these studies were younger (less than 50 years), an age range in which screening mammography is less effective in reducing mortality relative to older women, Gotzche and Nielsen revised their recommendations. They suggest that health organizations reconsider recommending screening mammography for women at average risk of developing breast cancer, because the benefits of screening mammography for women, even for women aged 50 and over, may not outweigh the harms associated with screening, such as over-diagnosis.

A recently published Canadian study also questions screening mammography benefits. Miller et al. (2014) followed 89,835 women in five Canadian provinces who were randomized to receive either screening mammography with a clinical breast exam or to receive a clinical breast exam only between 1980 and 1985. After 15 years, the difference in cumulative mortality from breast cancer between the groups was non-significant (hazard ratio, which compares the difference in rates between the two study groups over the 15-year period, was 0.99, 95% CI 0.88-1.12). The hazard ratio for women aged 40-49 years after 25 years was 1.09 (95% CI 0.80-1.49) and for women aged 50-59 years it was 1.02 (95% CI 0.77-1.36), indicating that the reduction in cumulative breast cancer mortality was non-significant for women in both age groups. In other words, the authors found that screening mammography did not significantly reduce cumulative breast cancer mortality. Given the lack of significant results in their study, these authors also conclude that health organizations should reconsider recommending screening mammography, because the benefits of screening mammography may be less than initially thought.

Following publication of Miller et al.'s (2014) study, many health organizations issued press releases to the public recommending that women still undergo screening mammography. In

spite of the results of the Miller et al. (2014) study, Cancer Care Ontario (Feb. 13, 2014) and the Canadian Cancer Society (Feb. 13, 2014) still recommend that women aged 50 and older should undergo regular screening mammograms, based on research prior to 2011 demonstrating the effectiveness of screening mammography.

Their decision not to reverse recommendations appears to have been appropriate, as an even more recent study contradicts Miller et al.'s (2014) conclusions by suggesting that the benefits of screening mammography outweigh the harms (Weedon-Fekjaer, Romunstad, & Vatten, 2014). This prospective cohort study was conducted in Norway during introduction of a screening mammography program from 1986 to 2009 for women aged 50-79 years. While the exact number of women participating in the study varied over the study period, 638,238 women were being observed in the year 2000, and the study included 15,193,034 person years of observation. Thus, the sample was much larger than in Miller et al.'s (2014) study. These researchers report there were 1175 deaths attributed to breast cancer in the screening group and 8996 deaths attributed to breast cancer in women who did not attend screening, with a mortality rate ratio of 0.72 (95% CI 0.69-0.79). This suggests a positive effect of screening mammography on breast cancer mortality. These authors do suggest that their results are comparable to other European studies, and that screening mammography should still be recommended for women in the 50-79 year age group. It is also important to note that the Miller et al. (2014) study included women under age 50, which may be one reason for the differing results, given that earlier studies have found that screening mammography is less effective in reducing breast cancer screening mortality in women in this age group (CTFPHC, 2011).

In summary, there is mixed evidence regarding the degree of benefits and risk related to screening mammography. Interestingly, two large-scale studies have reported contradictory

results. The Canadian study has suggested that routine screening mammography for women may be less beneficial than previously thought, although it should be noted it included participants under age 50, an age group in which earlier evidence has shown that screening mammography is less effective in reducing breast cancer related mortality (i.e. CTFPHC, 2011).. Alternatively, a recently published Norwegian study demonstrated that screening mammography is beneficial for women aged 50-79 years. In light of this mixed evidence, major Canadian health organizations still recommend that women in this age group undergo screening mammography. In contrast, most organizations recommend against screening mammography in women under the age of 50 years, given the greater harms associated with screening mammography in this age group, and the lack of clear evidence for the benefits of screening mammography for these younger women. In view of these ongoing recommendations and the related research, the current study will assume that healthcare providers should still recommend screening mammography to all women aged 50-74 years.

Cervical Cancer Screening

Unlike the recent debate as to whether women aged 50 years and older should receive screening mammography, the effectiveness of cervical cancer screening in preventing cervical cancer deaths has not been debated in recent years. In Canada, the British Columbia Cancer Agency (BCCA, 2016), the Canadian Task Force on Preventive Health Care (CTFPHC, 2013), and Cancer Care Ontario (CCO, 2015b) all offer cervical cancer screening recommendations for average-risk women. As with recommendations regarding screening mammography, recommendations between countries do not differ substantially, although the recommended age ranges, screening modalities and screening intervals do vary.

Cervical cancer screening recommendations.

Most organizations in the US, including the American College of Obstetricians and Gynecologists (ACOG, 2012), the American Cancer Society, the American Society for Colposcopy and Cervical Pathology, and American Society for Clinical Pathology (ACS/ASCCP/ASCP, 2012), and the United States Preventive Services Task Force (Moyer & USPSTF, 2012) recommend that cervical cancer screening should commence at age 21 years. Regionally, the British Columbia Cancer Agency (BCCA, 2016) recommends that women commence cervical cancer screening at age 21 years, or within three years after first sexual contact, whichever comes first. Finally, the Canadian Task Force on Preventive Health Care (CTFPHC, 2012) and the UK National Health Service (NHS) Cervical Screening Programme (2015b) recommend that women begin screening only slightly later, at age 25 years. Thus, across organizations and countries, screening recommendations for cervical cancer are relatively consistent in regards to the recommended age for commencing screening.

There are two methods of screening for cervical cancer. The first, cervical cytology testing, involves a physician taking a sample from the cervix. A pathologist then examines the tissue for biological changes indicating cancerous cells. The second, called “co-testing,” occurs when a cervical cytology test is combined with testing for the presence of Human Papilloma Virus (HPV). HPV has been found to be necessary, but not sufficient, for a woman to develop cervical cancer (National Cancer Institute, 2015). There are some differences in the method of screening and screening interval that health organizations recommend, with recommendations by American organizations differing from recommendations by organizations in Canada and the UK.

The BCCA (2016) and CTFPHC (2012), in contrast to American organizations, recommend against co-testing, citing the lack of evidence that it is effective in reducing cervical cancer incidence. However, the CCO (2015) and NHS (2015b) are exploring whether to incorporate HPV testing as part of routine screening. In contrast to American guidelines, in Canada, the recommended screening interval is also shorter, relative to the US. The BCCA recommends that women undergo cervical cytology screening every year, switching to every three years after three consecutive negative tests. The CCO states Canadian women should be screened every three years if the initial test is normal. The CTFPHC also recommends screening every three years for women, regardless of previous screening results. In the UK, the NHS recommends that cervical cytology screening occur every three years for women aged 25-49 years, and then every five years for women aged 50-64 years.

The US approach differs. Professional organizations and government bodies frequently recommend co-testing in order to lengthen the interval between tests, because co-testing for HPV increases the sensitivity of the cervical cancer screening test. The ACOG (2012), the ACS/ASCCP/ASCP (2012), and the USPSTF (2012) recommend screening cytology alone every three years for women aged 21-29 years. Because this group is more likely to have a positive HPV co-test, and in this age group HPV is less predictive of cervical cancer, HPV testing in this group is not recommended. Co-testing every five years is preferred for women aged 30-65 years. However, women aged 30-65 years may opt for cervical cytology screening every three years instead. Thus, unlike in Canada and the UK, in the US HPV screening is more strongly recommended and in practice may be more routine.

Organizations in Canada and the US state that cervical cancer screening can cease in older women. For Canadian women, the BCCA (2016), CTFPHC (2012), and CCO (2015)

recommend discontinuation for women aged 70 and older if they have had three consecutive negative tests in the previous ten years. Somewhat different, in the US, the ACOG (2012), ACS/ASCCP/ASCP (2012), and the USPSTF (2012) state screening may cease at age 65 if a woman has had three consecutive negative cervical cytology tests or two consecutive negative co-tests in the previous ten years. The reason for ceasing screening in older women is that cervical cancer is rare in older women. It also usually occurs in women who did not adhere to screening guidelines when they were younger, and thus did not have their cancer detected at an earlier age.

In summary, although there is some debate as to whether women should be routinely tested for HPV, there is consensus about the age range for cervical cancer screening. All organizations recommend that screening commence in women in their 20's, and that they receive cervical cytology screening every three years. Recommendations do differ slightly for women over age 30, but most organizations state that screening can cease in older women who have been regularly screened and who lack a history of abnormal findings, because new cases of cervical cancer are rare in this age group. These recommendations are supported by current research examining cervical cancer screening.

Evidence for cervical cancer screening.

In comparison to research regarding breast cancer screening, much less research has been conducted regarding the most effective cervical cancer screening protocol. A systematic review conducted by the Canadian Task Force on Preventive Health Care (CTFPHC) in 2012 identified only twelve case control studies of cervical cytology screening. The pooled odds of having had a cervical cancer screening test were higher among women without invasive cervical cancer (OR = 0.35, 95% CI 0.30-0.41), indicating that women who had been screened were less likely to have

advanced cervical cancer at diagnosis. The CTFPHC also evaluated the optimal interval between tests, and found that while the shortest interval (two to three years) offered the most protection, intervals of five years or less still offered substantial protection, and intervals of 10 years, or even 15 years, still offered some protection. Based on this research, the CTFPHC recommends a screening interval of three years for Canadian women.

In the US, research regarding the optimal screening interval, and the effect of adding HPV testing to screening protocols, has been explored. In 2012, Saslow et al. conducted a systematic review on behalf of the American Cancer Society, the American Society for Colposcopy and Cervical Pathology, and the American Society for Clinical Pathology. Based on the results, Saslow et al. concluded that women under 21 years of age should not be routinely screened, because the incidence of cervical cancer is so low in this age group, and the risk of false positives is higher than for older women. For women aged 21-29 years, they recommend cervical cytology testing only every three years, rather than every two years, which was the interval that was previously recommended. Saslow et al. also recommend against HPV co-testing in this age group, because HPV is highly prevalent in this age group, making a false positive result more likely, leading to unnecessary follow-up testing.

Saslow et al. (2012) do recommend HPV co-testing in women aged 30-65 years. Their rationale is that, because HPV is less prevalent in this population, a false positive test result is less likely. In addition, in women in this age group, the detection of HPV frequently indicates chronic HPV infection, which may contribute to pre-cancerous cervical lesions. Further, HPV testing increases the sensitivity of the screen. Based on their systematic review, Saslow et al. also recommend that screening can be ceased in women aged 65 years and older, if they have had two consecutive negative co-tests or three consecutive negative cervical cytology tests in the previous

10 years. Saslow et al.'s rationale is that for this age group, most cases of cervical cancer are in women who were not adherent to screening when they were younger and, because of this, did not have their cancer detected at a younger age.

In summary, the general consensus among healthcare organizations in Canada, the US and the UK is that women aged 21-65 years or 21-70 years should undergo regular cervical cancer screening. Unlike screening mammography recommendations, there is more consensus among researchers and organizations as to the age range for cervical cancer screening. However, there is debate concerning the optimal screening interval and the use of co-testing for HPV. In the 30 to 65 years age group, most Canadian organizations recommend screening every three years, while most American organizations recommend co-testing every five years. Finally, most organizations in Canada and the US agree that screening may cease at age 65 or 70 years if the woman has had two or three consecutive negative tests in the previous ten years. Hence, cervical cancer screening is recommended across a large age range, and recommendations are similar across organizations.

Colorectal Cancer Screening

The final form of screening to be discussed is aimed at detecting colorectal cancer. Discussions regarding this form of cancer screening have also led to debate regarding the optimal method. As with cervical cancer screening, US recommendations appear to differ from those in Canada and the UK. Of the recommended forms of colorectal cancer screening, the least invasive are 1) the fecal occult blood tests (FOBTs), which detect blood in the stool, including guaiac-based tests which detect heme (iron) from hemoglobin in the blood; and 2) fecal immunochemical tests (FIT), which have antibodies that detect the globin portion of hemoglobin.

Both are based on the premise that blood in the stool may be an indication that the individual has a colorectal cancer tumour or a pre-cancerous polyp, which could become malignant.

An alternate approach is to use screening colonoscopy or screening flexible sigmoidoscopy to detect colorectal cancer and pre-cancerous polyps in average-risk individuals. In both cases, an endoscopic camera is inserted through the lower colon or large intestine (sigmoidoscopy) or the entire colon (colonoscopy) to visualize the colon walls. This allows the physician to identify any cancerous tumors or pre-cancerous polyps. Some organizations have recommended a multi-phase screen: FOBTs or FITs for those at average risk of developing colorectal cancer, and colonoscopies or sigmoidoscopies for individuals at greater risk, or patients who have had a positive result from an FOBT or FIT. Other organizations, primarily in the US, recommend sigmoidoscopy or colonoscopies as the first step in colorectal cancer screening for individuals at average risk. These differences in screening approach are detailed in the next section, prior to reviewing the evidence in favour of each type of screening program.

Colorectal cancer screening recommendations.

Many Canadian organizations, including the British Columbia Cancer Agency (BCCA, 2016), the Canadian Cancer Society (CCS, 2014), and Cancer Care Ontario (CCO, 2016) recommend that those 50 years or older, who are at average risk, undergo a guaiac-based FOBT or FIT every two years. The Canadian Task Force on Preventive Health Care (CTFPHC, 2001a) also recommends FOBT testing every one to two years. In the UK, the National Health Service (NHS) bowel cancer screening programme (2015c) recommends FOBT testing every two years for average-risk individuals aged 60-69 years, and the NHS is expanding the program to include biennial screening for those aged 70-74 years. In these countries, colonoscopy or flexible sigmoidoscopy are only recommended by these organizations for people at increased risk of

developing colorectal cancer due to a personal or family history of cancer, or for individuals who have a positive FOBT result and require further investigation.

Unlike the health organizations in Canada and the UK, American government bodies and professional organizations recommend screening colonoscopy as the first phase in colorectal cancer screening for average-risk individuals. The American College of Gastroenterologists (Dominic, McGarrity, Dignan, & Lengerich, 2009), recommend that all individuals aged 50 years and older undergo a screening colonoscopy every ten years. However, the ACS states that alternatives to screening colonoscopies every ten years are FOBTs every year or flexible sigmoidoscopy every five years. The ACG authors suggest one reason for preferring screening colonoscopies over FOBTs in their review (ACG, 2008), in that they believe that the body of evidence indicates that colonoscopies are better able to detect earlier stage cancers, relative to FOBTs. The consequence of colonoscopies' increased sensitivity is that they detect cancer when it is more curable, relative to FOBTs' sensitivity. Thus, the ACG recommends colonoscopy every ten years for average risk individuals, instead of FOBTs, because the ACG considers colonoscopy to be a more effective screening test for detecting colorectal cancer in average risk individuals.

In summary, organizations in Canada and the UK recommend regular FOBTs or FITs, while in the US regular screening colonoscopies are preferred. Furthermore, while Canada and the US recommend screening begin at age 50, the recommendation in the UK is to start at age 60 years. However, similar to Canadian organizations, the NHS in the UK states screening should cease in older individuals.

Evidence for colorectal cancer screening.

Many health organizations have conducted systematic reviews to assess the best methods of screening for colorectal cancer in average-risk individuals, including the optimal screening recommendations. It is important to note that many of these reviews were conducted several years ago and are no longer up-to-date with current research. This is relevant because the evidence for FITs, which are generally believed to be more effective than FOBTs, is more recent.

The Canadian Task Force on Preventive Health Care (CTFPHC) conducted a systematic review in 2001 that evaluated only guaiac-based FOBT, because at that time there was insufficient evidence to determine the effectiveness of FITs (CTFPHC, 2001b). The CTFPHC identified four large randomized control trials using the Hemoccult FOBT, and determined that use of this test resulted in a 15% relative risk reduction in colorectal cancer mortality. They also report evidence suggesting that flexible sigmoidoscopy, either with FOBT or by itself, also reduces colorectal cancer mortality. The CTFPHC states there was insufficient evidence for them to recommend flexible sigmoidoscopy as the primary method of colorectal cancer screening. Thus, they currently recommend biannual FOBTs as the first phase of screening.

In 2008, the Canadian Partnership Against Cancer (CPAC) conducted a systematic review of FOBTs. CPAC identified two studies that compared the performance of two different types of FOBTs, and eight studies evaluating one FOBT for colorectal cancer screening in comparison to colonoscopy. No randomized control trials evaluating FIT met their inclusion criteria. Thus, CPAC indicated there was insufficient evidence to recommend whether guaiac-based FOBTs or FITs are the most sensitive colorectal cancer screening tests. These authors did conclude there was evidence to support the use of FOBTs in screening for colorectal cancer, alongside screening colonoscopies for higher risk patients.

Also in 2008, the United States Preventive Services Task Force (USPSTF) conducted a systematic review. The USPSTF reports that, compared to guaiac-based FOBTs, FITs had relatively higher sensitivity, but lower specificity. Evidence such as this, indicating a continued lack of a clear gold standard is one stated reason the USPSTF continues to recommend screening colonoscopies in average risk individuals.

More recently, in 2011 and 2013, two systematic Cochrane reviews investigating the effectiveness of FOBTs and flexible sigmoidoscopy were published. Hewitson, Glasziou, Irwig, Towler, and Watson (2011) explored the effectiveness of a guaiac-based FOBT, called Hemocult. Based on four randomized control trials, they determined that this form of FOBT reduced colorectal cancer mortality by 16% (pooled relative risk: 0.84, 95% CI 0.78-0.90). Later, in a 2013 Cochrane review, Holme, Bretthauer, Fretheim, Odgaard-Jensen, and Hoff assessed the benefits of FOBT and of flexible sigmoidoscopy. This group identified four randomized control trials comparing FOBT to no screening, and five randomized control trials comparing sigmoidoscopy to no screening. For FOBT, the pooled relative risk of colorectal cancer mortality was 0.86 (95% CI 0.80-0.92) and for flexible sigmoidoscopy, the pooled relative risk was 0.72 (95% CI 0.65-0.79). This finding indicates that individuals receiving FOBTs and flexible sigmoidoscopy were significantly less likely to die from colorectal cancer, compared to a control group who had not received screening. Holme et al. also noted that colorectal cancer incidence was significantly reduced in those receiving flexible sigmoidoscopy (RR 0.82, 95% CI 0.73-0.90), while there was a nonsignificant reduction for groups receiving FOBT (RR=0.95, 95% CI 0.88-1.02). Therefore, they concluded that flexible sigmoidoscopy is superior to FOBTs at detecting pre-cancerous polyps and reducing colorectal cancer-related deaths.

In summary, it appears that FOBTs may reduce colorectal cancer mortality. Some health organizations, such as Cancer Care Ontario, concluded there is sufficient evidence for the implementation of population-based colorectal cancer screening programs using FOBTs. Other organizations, primarily in the US, continue to recommend colonoscopies for screening average-risk individuals for colorectal cancer (i.e. American College of Gastroenterologists 2008 guidelines). American organizations have concluded that the evidence in favour of FOBTs' effectiveness over screening colonoscopy is insufficient at this time. More research needs to be conducted to determine whether FOBTs are a cost-effective and efficient alternative to colonoscopy screening for average-risk individuals, and whether newer FITs are more effective than older FOBTs at detecting colorectal cancer and preventing colorectal cancer-related deaths. At the time of writing, the optimal form of colorectal cancer screening was still being debated. However, for the purposes of this research, the BCCA continues to recommend FOBTs or FITs as the first phase in screening individuals at average risk of developing colorectal cancer.

Chapter 2 Summary

Currently, most government bodies and professional organizations recommend screening mammography, cervical cancer screening tests, and colorectal cancer screening tests for most adults. The effectiveness of screening mammography is still debated, and organizations' guidelines differ for cervical and colorectal cancer screening. Despite the debate over screening mammography's effectiveness, most organizations, including Cancer Care Ontario and the Canadian Cancer Society still recommend screening mammography. In addition, there is also continued debate concerning whether women should be tested for HPV in addition to being screened for cervical cancer. Currently, most Canadian government bodies recommend against HPV and cervical cytology co-testing, unlike many American organizations, which recommend

HPV co-testing. Finally, there is some debate as to the optimal method of screening for colorectal cancer. Most Canadian government bodies recommend FOBTs as the first step in screening for colorectal cancer, while many US organizations recommend screening colonoscopies for average risk individuals.

Hence, while there is some discussion concerning the best screening methods, there is evidence that healthy individuals should undergo regular cervical and colorectal cancer screening and, at least for the present, screening mammography. Given that Canadian organizations recommend screening mammography, cervical cytology and FOBTs, these types of screening will be considered optimal in the present study. Of course, screening can only be effective if people can access it. Unfortunately, certain groups in the general population may have difficulty accessing the recommended screening protocols and consequently experience disparities. These disparities among certain identifiable groups from the general population are explored in the next chapter.

CHAPTER 3: Cancer Screening Disparities Experienced by the General Population

As discussed in the previous chapter, screening recommendations exist for breast, cervical and colorectal cancer. Despite these recommendations, certain groups of individuals from the general population experience disparities in accessing screening. Disparities have been identified in relation to ethnicity, education, income, and access to healthcare providers. Differences within groups based on one factor may also exist in relation to another factor, creating intersections of disparities. For example, a key consideration for American studies is whether individuals have private health insurance, because Americans have more limited publically-funded cancer screening programs aimed at the general population, relative to other countries. However, whether an individual has health insurance is also interrelated with education, income, and to a lesser degree, ethnicity. Consequently, it is important to consider all of these factors when focusing on each factor.

Although cancer screening disparities in relation to breast, cervical, and colorectal cancer will be discussed in this chapter, it is important to note that the bulk of existing research has examined screening mammography disparities, because this form of screening has been recommended for a longer time period. Screening mammography has also been more widely promoted among members of the general public, and the adherence rates for screening mammography are higher than for other forms of screening. This makes it a more easily studied form of cancer screening from a feasibility standpoint.

In the following sections, studies examining disparities related to ethnicity, socioeconomic status (income and education), and access to healthcare providers, including having health insurance, will be reviewed for each type of screening. Many studies examining ethnicity and access to healthcare providers took place in the US, while studies that examine

differences by socioeconomic status and healthcare access in general were conducted in the US, Canada, European Union countries, and Argentina.

Screening Mammography Disparities

American researchers have identified significant differences in screening mammography rates among different ethnic groups. Disparities have also been identified in relation to income, education, age, and marital status, as well as ease of access to healthcare providers, including whether participants had health insurance. Disparities in relation to each major factor will be discussed independently, for the sake of comparison, although the studies included here may have investigated more than one factor. As stated above, it should be kept in mind that there is evidence that the factors are interrelated, and do not necessarily produce independent contributions to screening rates in the real world setting.

Screening mammography disparities experienced by women of differing ethnicities.

In most studies, Non-Hispanic whites have higher rates of screening mammography relative to other ethnic groups. Screening mammography rates have been found to be relatively high among this group: 63.4% in 1993 and 68.4% in 2005 (Sabatino et al., 2008), 78% in 2000 and 76% in 2005 (Mobley, Kuo, Driscoll, Clayton, & Anselin, 2008), 53.1% (Edwards et al. 2009), 75.4% (Miller, King, Joseph, Richardson, & CDC, 2012), and 81.4% (Bennett, Probst, & Bellinger, 2012). African Americans also frequently have relatively high rates: 76% in 2000 and 79% in 2005 (Mobley et al.), 44.0% (Edwards et al.), 78.6% (Miller et al.), and 82.2% (Bennett et al.) In contrast, Hispanic Americans have relatively lower rates: 41.6% (Edwards et al), 69% in 2000 and 70% in 2005 (Mobley et al.), as do Asian Americans: 57.1% in 2005 (Sabatino et al.) and 66% in 2000 and 78% in 2005 (Mobley et al). Finally, one study also reports that

American Indians have relatively lower rates (63.9%, Miller et al.). Although this data, collected across studies and settings, cannot confirm whether other potential factors are also at play, it does suggest a pattern in which Non-Hispanic White Americans have higher rates of screening, followed by African Americans and then by other ethnic groups. The fact that studies were also conducted over a period of almost 10 years also suggests that this pattern is long-term.

Two other American studies report using different criteria for examining screening rates among different ethnic groups. In Hawaii, Oh, Zhou, Kreps, and Ryu (2012) found that, compared to non-Hispanic whites, Pacific Islanders were more likely to have had a mammogram in the previous year (OR=1.87, 95% CI 1.85-1.90), while Asian Americans were less likely (OR=0.95, 95% CI 0.95-0.95). Oh et al. suggest that an educational program to increase screening mammography rates among Pacific Islanders underlies their results regarding that group. Consedine (2012) examined rates within multiple ethnic groups, and also used different criteria for screening adherence to mammography guidelines. Specifically, the study grouped participants as ‘fully adherent’, ‘partially adherent’, and ‘not adherent’, rather than using a dichotomous variable. In his study, Haitian immigrants and African Americans born in the US were more likely than US-born whites to be adherent to mammography, which is a very different pattern than that found in the other studies discussed. In addition, he found that Eastern European immigrants were less likely to be adherent to mammography, relative to the comparison group (US-born whites). Although Consedine does not comment on possible reasons for why his results differ from the majority of research, in that whites did not have the highest rates, the use of different criteria for measuring receipt of screening mammography may be one factor. In addition, the finding that whites did not have the highest rates in both the Oh et al. and Consedine studies may be due to the inclusion of different ethnic groups, Pacific Islanders and

Haitian immigrants, in their studies. Nonetheless, it is important that these studies did have differing results, because in addition to it highlighting the fact that ethnicity does not contribute to screening rates in isolation from other factors, they remind us that even ethnicity as a variable may not be static across geographic locations.

In contrast to the group of studies just discussed, some American researchers have not reported differences in screening mammography by ethnicity. Kim and Jang (2008) found no difference in rates related to ethnicity in their study of white and African American women from across the US, once they controlled for socioeconomic status. In another study comparing African Americans and non-Hispanic whites living in Michigan, by Akinyemiju et al. (2012), no differences between groups were found after controlling for age, income, marital status, and education. Finally, Fan, Mohile, Zhang, Fiscella, and Noyes (2012) did not report a difference across multiple ethnic groups after controlling for availability of healthcare providers in their study of non-Hispanic whites, Hispanic Americans, and African Americans living in both rural and urban communities. Thus, when researchers control for other variables, related to screening, such as factors related to socioeconomic status, differences across ethnic groups may be reduced, which is a reminder that ethnicity is interrelated with socioeconomic status and healthcare access.

Even with these three studies reporting no differences, the literature, when taken together, does indicate some differences in mammography screening rates in relation to ethnicity. In most studies, non-Hispanic whites and African Americans have the highest rates, followed by Hispanics, Asian Americans, and American Indians. In some specific geographic regions, other groups may have higher rates, apparently due to local initiatives or programs targeting groups within the general population. In addition, once other potentially confounding factors are

accounted for, such as socioeconomic status (Akinyemiju et al., Kim & Jang) or factors related to health care access (Fan et al.), differences across ethnic groups may also no longer be significant. Given this research suggesting interrelationships between ethnicity and socioeconomic status, it is also important to examine that possible contributor independently. The following section does so, and the subsequent section explores the role of access to healthcare providers in determining screening mammography rates.

Screening mammography disparities experienced by people with different socioeconomic status levels.

Socioeconomic status has many indicators, but is frequently defined by individuals' income and education. Several American studies, including Katz & Hofer (1994), Shootman and Jeffe (2003), Halliday, Taira, Davis, and Chan (2007), Kim and Jang (2008), Sabatino et al. (2008), Shi, Lebrun, Zhu, and Tsai (2011), Miller et al. (2012), Akinyemiju et al. (2012), Bennett et al. (2012), and Fan et al. (2012), have found that individuals with higher incomes, relative to individuals with lower incomes, were more likely to have received a mammogram within the studies' time periods. In addition to studies in the US, researchers in Israel (Wilf-Miron 2011), Italy (Damiani et al., 2012), Canada (Hofer & Katz, 1994), and Argentina (De Maio, Linetzky, & Ferrante 2012) have also reported that those with higher incomes were more also likely to have received a screening mammogram within their study time period. The consistency of these results across countries is informative. With the exception of the studies that were conducted in Argentina and the US, the remaining studies took place in countries that have more publically accessible healthcare. One would expect that access to healthcare should be relatively independent of individuals' incomes in these countries, and that they, therefore, would not have found differences due to income. That these authors did find significant differences due to

income suggests that other factors may have been involved, such as education (Kim & Jang, 2008), which is generally found to be associated with income, but also has independent effects that can impact how individuals access care.

Other researchers have not found significant differences in rates of screening mammography among different income groups (Park, Park, Choi, Jun, & Lee, 2011, Consedine, 2012, Couture, Nguyen, Alvarado, Velasquez, & Zunzunegui, 2012). Intriguingly, Consedine's study was conducted in the US, a country without a universal healthcare system, which is somewhat counterintuitive. Couture et al. conducted their study in Mexico, a country with a public healthcare system (even though it is not necessarily freely accessible) and the final study was conducted in Korea, a country with a freely available screening program (Park et al.). The lack of significant differences in rates by income level for these latter two studies is less surprising than Consedine's results, because one would assume that in a country with freely accessible screening, differences between groups from different income levels would be greatly reduced.

Further examination of Couture et al.'s (2012) study is also revealing. While they did not detect differences in screening rates by income, they did find differences related to education, with women who had a post-secondary education having a greater likelihood of having received a mammogram. The authors note that in Mexico certain professionals, such as civil servants, may have additional health insurance, which may make screening mammography more accessible. Thus, higher education may be related to having additional insurance (arguably a form of income) and ultimately higher screening rates. Park et al. (2011) did not find a difference by income or by education. This may be because they used the criterion of women never having received a mammogram, which is less stringent than other studies that did find differences when

examining annual or biennial screening rates. This may have attenuated any effects of income in their study.

As Couture et al. (2012) found, education level, which is also a component of socioeconomic status, can be related to receipt of mammography. As previously mentioned, it is important to consider that education and income are highly inter-related, because individuals with secondary or post-secondary education typically have higher incomes relative to individuals who do not complete secondary school. Several studies have found significant differences in screening mammography rates in the US among women with different educational levels (Katz & Hofer, 1994; Shootman & Jeffe, 2003; Kim & Jang, 2008; Shi et al., 2011; Akinyemiju, et al., 2012; Consedine., 2012; Edwards et al., 2009; Fan et al., 2012; Miller et al., 2012; Oh et al., 2012). In general, women with post-secondary education have higher screening mammography rates than those with a secondary school education or less. Researchers in Israel (Wilf-Miron et al., 2011), Italy (Damiani et al., 2012), Mexico (Couture et al., 2012), Canada (Katz & Hofer, 1994), and Argentina (De Maio et al., 2012) have also identified differences in rates in relation to education. With the exception of Argentina, these countries have universal healthcare, which means that screening is presumably more accessible in these countries. This group of studies suggests that, in spite of universal healthcare, which should reduce both the independent effect of income as well as any effect it has in conjunction with education, screening rates can be impacted by education level. This raises the possibility that other potential factors inter-related with education, such as literacy, may have a role in screening rates. Bennett et al. (2012) are the only group to find that education was not significantly related to screening rates. This may have been due to their having dichotomized education (less than high school vs. high school graduate

or post-secondary education), which would have reduced variability in their data and may have consequently reduced their ability to detect differences.

More research is needed to determine if the differences in screening rates across different education and income levels observed in many studies are due to the independent contributions of these factors, or whether these two factors merely moderate or modulate the influence of healthcare access on screening rates. One study, by Palencia et al. (2010,) may shed some light on this. Palencia et al. examined rates in several European Union countries, including some countries with national public screening programs, some countries with regional programs, and some countries without any publically funded programs. Palencia et al. found no differences due to education in countries with national population-based programs. In countries with regional population-based programs, or no population-based programs, some countries did display differences in screening rates by level of education. Their findings suggest that education, and possibly income, are not inherently related to screening differences. Rather, it is possible that these factors are proxies for accessibility of healthcare providers and mammograms, with women with more education and more income presumably having more access to healthcare in many settings. This is a very key point because it may also speak to the possibility that previously discussed differences in rates by ethnicity, which some posit also reflect unequal distribution of income and education, may also reflect an underlying effect of healthcare access. Thus, healthcare access, to be discussed in the next section, may be a critical element in whether women receive screening mammography.

Screening mammography disparities due to healthcare access.

Because healthcare in the US is privatized, having private health insurance is an important consideration in examining healthcare access there and may, to some extent, be

considered a surrogate for access to screening. Several studies in the US have found that women with private health insurance have higher screening mammography rates (Sabatino et al., 2008; Shi et al., 2011; Miller et al., 2012), and higher likelihoods of having received screening mammography (Akinyemiju et al., 2012; Bennett et al., 2012; Consedine, 2012; Katz & Hofer, 1994; Kim & Jang, 2008; Oh et al., 2012; Shootman & Jeffe, 2003). Studies conducted in Mexico (Couture et al., 2012) and Korea (Park et al., 2001) also found that women with private health insurance were more likely to have received a screening mammogram. Although Mexico and Korea have universal healthcare systems, they are not necessarily easily accessible, and some individuals in these countries have additional private health insurance. Thus, it appears that whether a woman has health insurance is an important factor in determining whether she receives a mammogram. This is especially true in countries where free or easily affordable screening mammography is not offered through a universal healthcare system, but also in some countries with universal healthcare, but where screening may not be easily accessible.

Another measure of healthcare access is whether a woman has a regular healthcare provider. Several studies have shown that women with a regular healthcare provider, or a regular source of healthcare, are more likely to have received a screening mammogram (Bennett et al., 2012; Consedine, 2012; Kim & Jang, 2008; Miller et al., 2012; Oh et al., 2012; Sabatino et al., 2008).

As with other factors related to receipt of mammography, access to healthcare is inter-related with many other potential factors. Having a regular healthcare provider is confounded with having health insurance because women without health insurance would be less likely to have a regular healthcare provider. In addition, given that a recommendation for screening from a healthcare provider is related to receipt of screening mammography (Abdul-Malek et al.,

2008), having a regular source of care may indicate that these women are more likely to receive a recommendation for screening, and then obtain screening. Consequently, current research does not tell us whether having a regular healthcare provider in combination with having a physician's recommendation leads to receipt of screening mammography, or whether having a regular healthcare provider alone leads to more accessible screening.

Screening mammography disparities in relation to family situation.

Thus far, most of the factors (ethnicity, socioeconomic status, access to healthcare providers) discussed are tied to the individual, rather than to the individual's family situation. However, other factors, such as marital status and age, may be also related to screening mammography rates. Married women are likely to have both higher socioeconomic status and stronger social support networks, both of which may facilitate access to screening. While age may at first appear to be an individual factor, age is also related to family situation, because women in their forties are more likely than women in their fifties and sixties to have young children that require care. This may make attending screening mammography appointments more difficult. In addition, having adult children provides an additional source of social support for adult women, which may make receipt of screening more likely. Thus, because age is so closely linked to family situation, it is also often considered side by side with family factors.

Research indicates that women in their forties have lower screening mammography rates than women in their fifties and sixties (Bennett et al. 2012; Consedine et al., 2012; Edwards et al., 2009; Miller et al., 2012; Oh et al., 2012; Wilf-Miron et al., 2011). The only study with conflicting findings was conducted by Damiani et al. (2012) in Italy. They also report that women younger than age 50 were less likely to have received a mammogram. However, they also report that was the case for women 55 years and older. Of note, most screening

mammography guidelines no longer recommend screening mammography in women younger than age 50. However, these current guidelines were only published after 2011. Because of this, many earlier studies, and even studies published after 2011, use data from time periods when screening mammography among women aged 40-49 years was still recommended. Therefore, the finding by the majority of researchers that younger women were less likely to have received a mammogram more likely reflects the role of family responsibilities or the possibility that older women have increased support from adult children than that women under age 50 were discouraged from obtaining mammograms according to guidelines in use at that time.

In addition to age, being married is also related to receipt of screening mammography (Akinyemiju et al., 2012; Bennett et al., 2012; Couture et al., 2012; Damiani et al., 2012; Oh et al., 2012; Park et al., 2011; Shi et al., 2011). One potential reason for this could be that married women experience more social support from their spouses, because social support has been found to facilitate obtaining screening mammography (e.g. Truesdale-Kennedy, Taggart, & McIlfatrick, 2011). Women who are married may also be more likely to have higher levels of income, a factor which has also been shown to be positively associated with screening mammography rates (e.g. Kim & Jang, 2008). Thus, the interrelationships between the many factors that can facilitate or hinder receipt of screening continue to be a consideration in understanding the role of any individual factor.

In conclusion, ethnicity, socioeconomic status, access to healthcare, and family situation are all interrelated, and appear to each be related to receipt of screening mammography. Because of the high inter-correlation among these factors, however, further research is needed to identify the unique contributions of each factor to obtaining screening mammography.

Cervical Cancer Screening Disparities Experienced by the General Population

Researchers have also examined disparities in cervical cancer screening due to ethnicity, socioeconomic status and access to healthcare. A key consideration is that most screening mammography disparity studies discussed in the previous section were conducted in the US, while many of the cervical cancer screening disparities studies that will be described in this section were conducted in other countries that have universal healthcare. Disparities were still found in many of these studies, suggesting freely accessible screening alone does not necessarily eliminate disparities. Disparities between and within ethnic groups are reviewed first, followed by disparities due to socioeconomic status, then disparities due to healthcare access. Researchers have not examined the effect of age and marital status on cervical cancer screening rates among women from the general population.

Cervical cancer screening disparities experienced in relation to ethnicity.

An early study concerning ethnic disparities examined participation in cervical cancer screening by First Nations women in BC (Hislop, Deschamps, Band, Smith, & Clarke, 1992). Hislop et al. report that 52.0% of participants were recent users (had a Pap smear in the previous three years), and 19.8% were ex-users (received their last Pap smear more than three years ago). The rate of recent users was lower than the 85% reported for the general population in the 1986 BC population census data. No data were available for comparison of ex-user rates with the general population.

Later, Hislop et al. (2003) examined cervical cancer screening rates among Chinese Canadian women living in the Greater Vancouver Area. Previous research suggested that Chinese Canadian women have lower cervical cancer screening rates relative to the general

population, and the authors wanted to determine if these lower rates occurred across all subgroups of Chinese Canadian women living in different geographic areas of Vancouver, with varying degrees of access to healthcare services. The proportion of women who had ever had a Pap smear varied by neighbourhood, with rates ranging from 32.3% to 83.8%, and the percentage of women who had been tested within the last two years ranged from 12.9% to 63.9%. The authors suggest that a reason for this variability may have been that neighbourhoods varied greatly by education, income, marital status, country of birth, and availability of physicians. Thus, when examining disparities between ethnic groups, it is important to consider the fact that socioeconomic factors don't only vary between ethnic groups, they may also vary within groups and may have an effect as they would in the general population.

In Ontario, researchers have examined cervical cancer screening by immigration status. Khadilkar and Chen (2013) found that women who had immigrated to Canada less than ten years prior to the start of the study were significantly less likely to have obtained a Pap smear in the previous three years, relative to Canadian-born women (PR=0.77, 95% CI 0.71-0.84). Interestingly, women who had lived in Canada ten years or longer had rates comparable to Canadian-born women, suggesting that the impact of being an immigrant to Canada on healthcare access may not be permanent. Lofters, Hwang, Moneddin, and Glazier (2011) also examined screening rates among immigrant women, and found that while 53.1% of immigrant women living in urban regions of Ontario had had a Pap smear in the previous three years, 64.6% of long-term residents had had a screen in the same time period. This adds to the evidence that the negative effects of being an immigrant on cervical cancer screening rates reduces with time since immigration.

Thus, cervical cancer screening rates are lower in certain groups, including First Nations women and women who are recent immigrants. It is important to note within ethnic groups, there may be disparities among different socioeconomic status groups, and healthcare access may also be unequal, even in countries with universal healthcare. In addition, it appears that the effect of being an immigrant may decrease over time, suggesting that having more time in the country may improve access. The contribution of educational level and income levels to receipt of cervical cancer screening, which potentially are also related to time since immigration, are explored in the next section.

Cervical cancer screening disparities in relation to socioeconomic status level.

Unlike studies of screening mammography, which have primarily been conducted in North America, studies that have reported an impact of socioeconomic status on cervical cancer screening rates have taken place in a wide range of countries, suggesting this is a robust effect. One study to examine cervical cancer screening among different socioeconomic groups was conducted in both Canada and the US, and another study was conducted in Puerto Rico. The first study found that women with annual incomes greater than \$46,500 were more likely to have been screened (Katz & Hofer, 1994) and the second found women with an income less than \$15,000 were less likely to have been screened (Ortiz et al., 2010). Studies in Argentina (De Maio et al., 2012) and Korea (Lee et al., 2013) have also found that women with higher income levels were also more likely to have been screened. Puigpinos-Riera et al. (2011) also report that women from higher social classes in Spain, with presumably higher incomes, were more likely to be screened. Finally, a French study by Rigal, Saurel-Cubizolles, Falcoff, Bouyer, and Ringa (2011) found that women within a lower occupational class, or who had financial difficulties, a smaller social network, or lower neighbourhood safety, were all less likely to have obtained

screening. Overall, these studies demonstrate that women with higher incomes generally have higher screening rates, relative to women with lower incomes, a similar pattern to that found for screening mammography (Palencia et al., 2010).

Disparities in cervical cancer screening by education have also been reported. De Maio et al. (2012) in Argentina and Lee et al. (2013) in Korea both report that women in their studies with higher levels of education were more likely to have received screening. Bennett et al. (2012) report that American women with less than a high school education were less likely to have been screened, and an Italian group of researchers (Damiani et al., 2012) found that women with secondary school or higher were more likely than women with only a primary school education to have been screened. Finally, Mexican researchers (Couture et al., 2012) also found that women who were illiterate were less likely to have been screened, compared to women with a secondary school education or a post-secondary education. Therefore, as with income level, researchers in multiple countries have found that increased education is associated with a greater likelihood of having been screened.

These two groups of studies, examining key components of socioeconomic status, income and education level, provide strong evidence that socioeconomic status is associated with receipt of cervical cancer screening by women. Although the studies did not determine a causal pathway, the impact may be due to women with higher socioeconomic status, including higher education, having health insurance and greater access to healthcare providers. Alternatively, women with more education may be more knowledgeable about the need for screening, and seek out screening. Recent media campaigns encouraging cervical cancer screening use print media. Because of this, women with higher socioeconomic status, typically having higher literacy levels than those of lower socioeconomic status, may be more influenced by them. Further research is

needed to uncover these complex relations, and determine the contribution of income and education to screening rates.

Cervical cancer screening disparities in relation to healthcare access.

A related factor that also must be considered is the accessibility of healthcare, because it may also have effects on whether women of any socioeconomic background can gain screening. Some studies suggest unequal healthcare access is also an independent contributor to cervical cancer screening rates. Researchers have measured healthcare access by whether participants have health insurance, or whether participants have a family physician or have routine medical check-ups. Women with higher socioeconomic status are more likely to have health insurance in countries without universal public healthcare systems (Sabatino et al., 2008), increasing their access to healthcare. This finding suggests that, when reviewing studies that have examined differences in screening by access to healthcare, it is important to consider this potential relationship.

Four studies, one in Mexico, two in the US, and one in Korea, report that participants who had health insurance were more likely to have obtained a Pap smear in the previous two to three years (Bennett et al., 2012; Couture et al., 2012; Katz & Hofer, 1994; Park et al., 2011). However, having health insurance appears to primarily play a substantial role in screening rates in countries without universal publically-funded healthcare systems. Katz and Hofer, who also included data from Canada, only found a difference in rates among women in relation to health insurance in the US, not in Canada. The authors suggest this may be due to Canada's universal healthcare system, suggesting the impact of having health insurance may be limited to countries where there is no, or limited, public healthcare.

In addition to having health insurance, researchers report that women with a family doctor (Qi, Phillips, & Hopman, 2006), women in a primary care enrollment model (patients who receive care from primary care health professionals rather than specialists, Lofters et al., 2010), and women who received a routine medical check-up in the previous year (Ortiz et al., 2010) were all more likely to have been screened in the previous three years. Importantly, the studies by Qi et al. and Lofters et al. both took place in Canada, a country where access to healthcare is more equitable. Thus, as this small group of studies suggests, even in a more equitable healthcare system, disparities due to healthcare access may still exist.

In summary, the studies described in this section explored the roles of ethnicity, socioeconomic status, and access to healthcare in contributing to cervical cancer screening disparities. This research suggests that the contributions of ethnicity, socioeconomic status, and healthcare access overlap. Even in countries with relatively accessible healthcare, these factors may still contribute to disparities, in contrast to the findings in regard to breast cancer, for which studies have found that having an accessible, universal public healthcare system largely eliminates disparities related to these factors.

Colorectal Cancer Screening Disparities Experienced by the General Population

Colorectal cancer screening disparities due to ethnicity, socioeconomic status, and health care access exist among certain subgroups, similar to breast and cervical cancer screening disparities. Unlike breast and cervical cancer screening criteria, researchers use multiple criteria to explore receipt of colorectal cancer screening. In most studies, individuals who received any type of colorectal cancer screening within the recommended time period (fecal occult blood test in previous year, sigmoidoscopy in previous five years, colonoscopy in previous 10 years), were considered to have been screened. In other studies, primarily in the US where colonoscopies are

still recommended as the primary method of colorectal cancer screening in average-risk individuals, only participants who had received a colonoscopy were considered to have been screened. This variation makes it more difficult to compare the results of colorectal cancer screening studies to each other and to breast and cervical cancer screening studies.

Colorectal cancer screening disparities experienced in relation to ethnicity.

All but one American study found that whites and African Americans had higher colorectal cancer screening rates, while Hispanics, Asian Americans, and American Indians/Alaskan Natives had lower colorectal cancer screening rates (Bennett et al., 2012; Harmon et al., 2014; Liss & Baker, 2014; Shi et al., 2011). Only May et al. (2014) found that African Americans had significantly lower odds of receiving any screening and colonoscopy, compared to whites (OR= 0.49, 95% CI 0.31-0.77 for any type of screening; OR=0.43, 95% CI 0.24-0.77 for colonoscopy exclusively). A closer look also reveals that US-born Hispanics, relative to Mexican-born Hispanics, and Hispanics whose preferred language is English relative to Hispanics whose preferred language is Spanish, have higher rates of screening (Harmon et al., 2014; Liss & Baker, 2014). However, the rates are still lower than US-born whites. Because it is very likely that Mexican-born Hispanics also prefer to use Spanish, this suggests that the language spoken by physicians may be a barrier to obtaining colorectal cancer screening for Hispanics whose preferred language is Spanish. However, it may also be that recent immigrants face barriers to accessing screening beyond language issues. This is a reminder that, even within ethnic groups, there may be variations in the effects of factors impacting screening rates.

I identified only one study examining colorectal cancer screening disparities caused by ethnicity that was conducted outside of the US. This study was conducted in Israel. Wilf-Miron et al. (2011) found that immigrants and Israeli Arabs, relative to other Israeli citizens, had lower

colorectal cancer screening rates (OR=0.789, 95% CI 0.735-0.846 for Arabs, OR=0.832 95% CI 0.814-0.851 for immigrants). This finding is in spite of the study having been conducted in a country with universal public healthcare, which one would have expected to attenuate differences. This suggests that being a recent immigrant or a minority population, as in the US studies, may lead to difficulties in accessing screening.

Together, the disparities revealed in both the American and Israeli studies suggest that characteristics that are often associated with ethnicity, such as language barriers or being new to a country, may contribute to disparities. This could be due to the direct effects of these. It could also be that language barriers and recent immigration lead to other factors, such as reduced knowledge of screening availability, lower socioeconomic status, or limited access to healthcare services for practical reasons (e.g. lack of transportation). Regardless, the fact that the Israeli study found differences within a universal public healthcare system supports the hypothesis that ethnic characteristics make unique contributions to disparities, as does the American study that found that the language spoken by patients influenced screening rates.

Colorectal cancer screening disparities in relation to socioeconomic status level and access to healthcare.

The only study to have specifically examined disparities by markers for socioeconomic status, such as education level, was conducted by Harmon et al. (2014). They report that individuals who had some college education, in comparison to no college education, were more likely to have been screened (OR 1.47, 95% CI 1.43-1.51). Although no other study could be found that examined screening differences in relation to specific markers for socioeconomic status, some groups have looked at access to screening and their results speak indirectly to socioeconomic status.

Similar to breast and cervical cancer screening, having health insurance is a factor in receipt of colorectal cancer screening. Shi et al. (2011) and Wilf-Miron et al. (2011) both report that individuals with health insurance in their studies were more likely to have received colorectal cancer screening than those without insurance (Shi et al.: 44% private vs. 20% uninsured in 2000; 60% private vs. 21% uninsured in 2008; Wilf-Miron et al.: OR=1.824, 95% CI 1.756-1.885). Thus, receipt of colorectal cancer screening appears to be associated with having health insurance, both in countries with (Israel; Wilf-Miron et al.) and without (US; Shi et al.) universal healthcare. These results, although indirect, support the premise that socioeconomic status is a factor in colorectal cancer screening.

Colorectal cancer screening disparities in relation to geographic area.

Another consideration in understanding colorectal cancer screening disparities is geographic area, because a more rural region would presumably have fewer healthcare professionals and healthcare resources than an urban region. Particularly in the US, where colonoscopy is recommended, colorectal cancer screening is more resource intensive and requires specially trained physicians relative to other screening modalities. Three studies, one by Fan et al. (2012) and two by Cole, Jackson, and Doescher (2012, 2013), demonstrate that rural residents are less likely to have been screened relative to their urban counterparts. Fan et al. report that individuals in isolated rural regions and small rural regions had lower odds of receiving colorectal cancer screening than those in urban areas (small rural OR =0.69 (95% CI 0.56-0.84) isolated rural OR=0.56 (95% CI 0.46-0.68)). Cole et al. (2012) also report that rural residents had lower rates in comparison to urban residents (rural residents 48% (95% CI 48-49%) vs. urban residents 54% (95% CI 53-55%)). Finally Cole et al. (2013) found that rural African Americans, relative to urban African Americans, and rural Hispanics, relative to urban

Hispanics, had lower colorectal cancer screening rates (African Americans 44.8% rural vs 52.8% urban, $p < 0.05$; Hispanics 40.8% rural vs. 43.7% urban, $p < 0.05$). As discussed above, colorectal cancer screening by colonoscopy, whether as a primary or secondary method of screening, requires specialized physicians, and is more resource intensive, requiring specialized medical equipment. In rural areas there may be fewer physicians trained to perform colonoscopies, or patients may need to travel a greater distance to obtain screening, which may decrease screening rates and, account for the disparities by geographic region found.

In summary, colorectal cancer screening rates have been shown to vary by ethnicity, educational level, access of health insurance, and geographic regions. This limited number of studies, relative to other types of screening, may reflect the lack of promotion of this type of cancer screening by healthcare professionals. In addition, relative to breast and cervical cancer screening disparities, colorectal cancer screening disparities have not been as well investigated in the US and studies are more recent. Given that colorectal cancer screening has not been promoted by health organizations to the same extent as screening mammography and cervical cancer screening, it is possible that if this mode of screening becomes more widely adopted, emerging research will demonstrate that the factors related to receipt of screening for breast and cervical cancer screening also apply to colorectal cancer screening.

Chapter 3 Summary

The focus of this chapter was to describe the existing literature examining disparities in accessing breast, cervical, and colorectal cancer screening experienced by subgroups of the general population. The research found indicates that disparities exist in relation to ethnicity, socioeconomic status, and access to healthcare professionals for all three forms of screening, in relation to family situation for screening mammography and in relation to geographic area in

regard to colorectal screening. Unfortunately, the small number of studies and variability in samples, settings and designs, makes it difficult to untangle the relative and independent contributions of these factors to all three types of screening. This is an important task for future researchers. Although the existing literature provides evidence that all factors play a role, the current body of research does not provide sufficient evidence to guide potential programs or policies that would be most effective at addressing the unique impact of any one.

While multiple groups were included in the research discussed above, none of the studies discussed included individuals with Intellectual Disabilities. This means there is no direct evidence that these factors impact screening rates for individuals with Intellectual Disabilities. Conversely, there is also no evidence that these factors should not apply to this specific group. Moreover, there is also research that suggests that, regardless of the factors that impact receipt of cancer screening that have been identified for the population as a whole, those with Intellectual Disabilities face additional barriers to accessing screening for breast, cervical and colorectal cancer that may further increase their risk for negative outcomes. These will be the focus of the next chapter.

CHAPTER 4: Cancer Screening Disparities Experienced by Individuals with Disabilities

As described in Chapter 3, certain groups in the general population experience breast, cervical, and colorectal cancer screening disparities. Individuals with disabilities, especially Intellectual Disabilities, may face additional difficulties in obtaining cancer screening, which results in further screening disparities. In this section, I review research that has explored disparities in obtaining screening for individuals with limitations in activity, physical disabilities, and Intellectual Disabilities.

Screening Mammography Disparities Experienced by Women with Disabilities

Several groups of women with disabilities experience disparities in accessing screening mammography, including women with limitations in daily activities, with physical disabilities, and with Intellectual Disabilities. In addition, women with disabilities have described barriers to obtaining screening mammography that they feel is directly related to their disability, such as how care is delivered by healthcare professionals. The disparities documented for women with different types of disabilities are discussed in this section, followed by a discussion of these women's experiences of obtaining screening mammography, and their families' experiences in supporting them to access screening.

Screening mammography disparities experienced by women with limitations in daily activities.

Researchers have used different criteria for defining disability when studying screening disparities experienced by women with disabilities. One of the most common and most inclusive definitions of disabilities is defining disability as any limitation in performing daily activities.

Researchers have also used self-report of limitations in activities of daily living or instrumental activities of daily living. It is important to keep the definition of disability used in mind when comparing studies, as the disparities they report do vary, and it is possible that the variability is due to sample differences based on their definition of disability.

Wei, Findley, and Sambamoorthi (2006) used the broadest definition of disability, defining it as any limitation in daily activity. Women in their study reporting any limitation in daily activity were 31% less likely to have received a mammogram in the previous two years than women from the general population (OR=0.69, 95% CI 0.51-0.95). Another frequently used definition of disability is that it is any limitation in performing activities of daily living, or limitations in performing instrumental activities in daily living (Caban, Kuo, Rajui, Tan, & Freeman, 2011; Shootman & Jeffe, 2003). Activities of daily living include day-to-day tasks involved with self-care such as bathing and dressing, while instrumental activities of daily living include tasks such as housework and using the telephone. When this definition was used, Shootman and Jeffe (2003) found that women with limitations in performing the activities of daily living had a 77% lower odds of receiving screening mammography (OR=0.23, 95% CI 0.1-0.41). Armour, Thierry, and Wolf (2009) defined disability as any limitation in daily activities due to physical, mental or emotional problems, or a limitation that necessitates special equipment. They also found that women meeting their criteria had a significantly lower screening mammography rate (72.2%) than women in the general population (77.8%, $p < 0.001$). The degree of disability may also affect the disparity found. Caban et al. (2011), who used a definition similar to that used by Shootman and Jeffe, found that, compared to women from the general population, women with moderate disabilities had a 24% lower odds (OR=0.76, 95% CI 0.64-0.91) of receiving screening mammography, and women with severe disabilities (OR=0.46,

95% CI 0.40-0.54) had a 54% lower odds of receiving screening mammography. Finally, women self-reporting disability also had lower screening mammography rates in a more recent study (65.7% for women with a disability vs. 81.4% not reporting a disability, $p=0.041$, Buckley, Davis, & Andresen, 2012). Thus, researchers who have used a broad definition of disability have found that women meeting their criteria for having a disability have significantly lower screening mammography rates than women in the general population.

Studies with more explicit definitions of disability have also reported differences in rates. Chevarley, Thierry, Gill, Ryerson, and Nosek (2006) found women with a greater number of functional limitations reported lower screening mammography rates (28.3%) than women without any limitations (37.9%, $p<0.01$). Interestingly, while Ahmed, Smith, Haber, and Belcon (2009) reported that women with social limitations were 38% less likely to have received a mammogram (OR=0.62, 95% CI 0.48-0.81), women with physical limitations were 28% more likely to have received a mammogram (OR=1.28, 95% CI 1.07-1.53), relative to women from the general population. Ahmed et al.'s study may reflect the fact that women with physical limitations may have relatively more access to healthcare providers than groups with other forms of disability, because they are typically followed within the healthcare system for their physical problem.

Taken together, these studies indicate that women with any type of disability or limitation in performing daily activities have lower screening mammography rates than women from the general population. Their rates of having received screening ranged from 5% to 15% below rates found for the general population, with a reported 24% to 77% lower odds of having received screening. Although the rates of screening varied by the definition of disability used, the majority of studies found women with any disability were less likely to receive screening mammography.

The one exception was that a subgroup of women with physical disabilities were more likely to have received a mammogram in one study (Ahmed et al., 200). In addition to these studies, others have investigated screening rates for women with Intellectual Disabilities specifically.

Screening mammography disparities experienced by women with Intellectual Disabilities.

Research indicates that women with Intellectual Disabilities face disparities in accessing healthcare, including obtaining screening mammography. Studies of receipt of screening mammography for women with Intellectual Disabilities have found consistent results across countries. A recent study in Ontario by Cobigo et al. (2013) found that women with an Intellectual Disability were 54% less likely to have received a mammogram in the previous two years (OR=0.46, 95% CI 0.43-0.49). An American study, by Reichard, Stolze, and Fox (2013), also found that women with Intellectual Disabilities were 69% more likely to not have received a mammogram in the previous two years (OR=1.69, 95% CI 1.30-2.20) and in a UK study, Osborn et al. (2012) found that women with Learning Disabilities were less likely to have received a mammogram in the previous three years (Incidence rate ratio=0.75; 95% CI 0.71-0.80). Australian women with Intellectual Disabilities also had lower rates of having received a mammogram in the previous two years in a study there (55.2% for women with Intellectual Disabilities, 95% CI 42.4-67.3%, 75.9% for women from the general population, 95% CI 74.5-77.2%; Haider, & Emerson, 2013).

Some studies have also compared groups with Intellectual Disabilities to other groups with disabilities. In a study of American women with Intellectual Disabilities, these women had higher rates of never having received a mammogram (26.8%, 95% CI 19.4-34.2%), compared both to women with physical disabilities (14.5%, 95% CI 10.5-19.7%), and women from the

general population (13.0%, 95% CI 10.3-16.3%; Havercamp, Scandlin, & Roth, 2004). Kung, Tai, and Chiou. (2012) examined screening mammography rates among women registered with the Taiwanese National Disability Registry. They examined the odds of receiving screening in women with multiple disabilities, visual impairment, and Intellectual Disabilities relative to women with physical disabilities. These authors report that, compared to women with physical disabilities, women with Intellectual Disabilities (OR=0.69, 95% CI 0.65-0.73) had lower odds of receiving a mammogram.

This small body of literature indicates that women with disabilities, including limitations in daily activities and Intellectual Disabilities, experience disparities in screening mammography. Further, it appears that women with Intellectual Disabilities also experience disparities in obtaining screening mammograms relative to women with physical disabilities. The reasons for these disparities are complex, and may be partly be due to the fact that women with disabilities are more likely to have lower socioeconomic status or education, or difficulty accessing healthcare. These factors, which have been shown to be related to disparities in screening mammography among women from the general population, may also be related to disparities experienced by women with Intellectual Disabilities. For example, Wilkinson, Lauer, Freund, and Rosen (2011) reported that women living in residential centres rather than with family (OR=1.32, 95% CI 1.14-1.53) and who received healthcare coordination from an RN (OR=1.40, 95% CI 1.21-1.63) both had higher odds of receiving screening mammography. Sullivan et al. (2003) found that women with an Intellectual Disability who were married (OR=2.52, 95% CI 1.21-1.63) and women who lived in rural areas (OR=2.07, 95% CI 1.11-3.85) also had higher odds of receiving screening mammography. These two studies highlight that factors impacting

receipt of mammography in the general population also contribute to rates within the population of women with Intellectual Disabilities.

It is also possible that women with disabilities face stigma due to their disability (Werner, Corrigan, Ditchman, & Sokol, 2012), or may have unique characteristics related to their disability, which makes accessing healthcare more difficult. For example, attitudes of healthcare professionals, a reduced understanding of the rationale for screening mammography on the part of the individual with an Intellectual Disability, or caregiver concerns about how the woman will handle the procedure may also play a role. These factors may also have differing impacts depending on the type of disability or combination of disabilities a woman experiences.

While the research discussed in this section demonstrates that women with disabilities experience screening mammography disparities relative to the general population, details about factors that facilitate screening or are barriers to screening were not often examined in detail. Although research examining the experiences of receiving screening mammography among women with disabilities using a qualitative methodology has been limited, the studies that do exist can provide some insights into factors that may lead to disparities. Accordingly, these studies are described in the next section.

Qualitative and descriptive studies describing screening mammography experiences of women with disabilities.

Several researchers have used qualitative methodologies or descriptive interviews to identify barriers to screening that may contribute to the disparities in screening mammography experienced by women with disabilities. For example, healthcare professionals and Intellectual Disability staff in two studies acknowledged that, although women should receive breast cancer

screening, women with Intellectual Disabilities often do not (McIlpatrick, Taggart, & Truesdale-Kennedy, 2011; Taggart, Truesdale-Kennedy, & McIlpatrick, 2011). Participants in both studies suggested the reason for this disparity is that women with Intellectual Disabilities may have difficulties with screening. Unfortunately, the authors of these studies did not have their participants elaborate on what they felt these difficulties were. Nonetheless, their findings do suggest that the existence of barriers is known to healthcare practitioners.

One very basic barrier frequently experienced by women with disabilities is arranging for transportation to and from the screening clinic, and accessibility at the clinic, especially for those with physical disabilities (Barr, Giannotti, Van Hoof, Mongoven, & Curry, 2008; Jarman, Bowling, Diekens, Luken & Yankaskas, 2012; Mele, Archer, & Pusch, 2005). Another barrier that has been described is a lack of health insurance (Mele et al.). These can be compounded by a lack of social support from family members (Barr et al., Suzuki, Krahn, Small, & Peterson, Besse, 2013).

Women with many types of disabilities also report that a barrier occurs when healthcare professionals lack knowledge about disabilities or have negative attitudes about women with disabilities. For example, women with physical and Intellectual Disabilities in Jarman et al.'s (2012) study state that some were told by their physician that breast cancer screening is not necessary for women with disabilities. Healthcare professionals also report that they lack knowledge about breast health, or required additional training in this area (Hanna, Taggart, & Cousins, 2011; Kirby & Hegarty, 2010; McIlpatrick et al., 2011; Tyler, Zyzanski, Panaite, & Council, 2010). This finding is surprising because participants in the Hanna et al., Kirby and Hegarty, and Taggart et al. studies were assessed to be knowledgeable regarding breast cancer risks and breast cancer screening in the general population. Similar to healthcare professionals,

support staff (Hanna et al., 2011) also report that they fail to educate women with Intellectual Disabilities concerning their need for breast cancer screening, in spite of the finding that support staff are knowledgeable regarding breast cancer screening for women in the general population. Although current guidelines (e.g. BCCA, 2016) do not discriminate between women with Intellectual Disabilities and women in the general population, it is possible that these professionals believed they need additional or more specific information for the women with Intellectual Disabilities that they work with. This finding does suggest that they viewed these women as different in some way from women in the general population.

Attitudes towards people with Intellectual Disabilities may also interact with a lack of knowledge on the part of healthcare providers. This possibility is supported by studies of women with physical disabilities who report that healthcare professionals have negative attitudes concerning their ability to comply with screening (Jarman et al., 2012; Llewellyn, Balandin, Poulos, & McCarthy, 2011; Mele et al., 2005). Similarly, Wilkinson, Deis, Bowne, and Bokhour (2011) report that women with Intellectual Disabilities stated that technicians made them feel singled out because of their disability, which made them less likely to seek out future screening. Thus, attitudes of healthcare providers may also interact with women's own beliefs and attitudes regarding screening, which may also affect whether they seek screening. In turn, their beliefs, as with healthcare providers, may also relate to a lack of knowledge.

Self-advocates (Parish, Swaine, Luken, Rose, & Dababnah, 2012; Truesdale-Kennedy et al., 2011; Wilkinson, Deis, et al., 2011) report that they lack knowledge concerning breast cancer screening or their personal risk of breast cancer (Llewellyn et al., Suzuki et al., 2013). Importantly, self-advocates also relate that this lack of knowledge contributes to their anxiety about the procedure (Truesdale-Kennedy et al.; Wilkinson, Deis, et al., 2011). Other attitudes or

beliefs on their part may also contribute to lower rates. For example, a lack of belief in the value of mammograms or skepticism about the benefits of mammograms have been reported (Barr et al., 2008; Llewellyn et al., 2011). As in relation to other factors impacting rates of mammography, facilitators have also been identified. Self-advocates report that a primary motivation to obtain a screening mammography was that they felt it was important, and because they wished to fit in with their peers (Wilkinson, Deis, et al., 2011). Other facilitators that have been described relate to women's personal beliefs about screening, including feeling susceptible to breast cancer due to a family history of breast cancer, valuing health promotion activities, having a desire to know whether or not she has cancer, and having religious beliefs in favour of screening (Kahn, Fox, Krause-Kelly, Berdin, & Cadzow, 2005; Miller, Lasser, & Becher, 2007). Thus, women with disabilities have many personal beliefs concerning breast cancer screening which may influence whether they seek out and obtain screening.

Another barrier described in relation to women with different types of disabilities is the pain or discomfort experienced during a prior mammogram (Kahn et al., 2005; Llewellyn et al., Miller et al., 2007). Some women interviewed in the studies also indicated that their comorbid physical disability may make screening mammography more difficult (McIlpatrick et al. 2011; Taggart et al., 2011). This is similar to the finding from studies of women with solely physical disabilities that report accessibility as being a barrier (Barr et al., 2008; Jarman et al., 2012; Mele et al., 2005; Miller et al., 2007).

Finally, there may be some barriers to screening mammography that are more specific to women with Intellectual Disabilities. One barrier is healthcare professionals' concerns about low literacy among women with Intellectual Disabilities, which may lead to difficulties with communication and obtaining consent (Kirby & Hegarty, 2010; McIlpatrick et al., 2011; Taggart

et al., 2011). Other barriers included healthcare professionals' perceptions that women with Intellectual Disabilities have poor attendance at screening (McIlpatrick et al., 2011) and as more likely to refuse to cooperate (Tyler et al., 2010).

In summary, women with disabilities, including women with Intellectual Disabilities, face disparities in obtaining screening mammography, and likely these disparities have a variety of causes. For all of the barriers described, women with disabilities may have fewer resources, such as a spouse or adult children, to help them to cope. This may be a factor regardless of whether they experience barriers to screening mammography related to the screening clinic itself, the healthcare professionals at the clinic, or their personal beliefs about screening mammography. While less extensively studied, women with disabilities also face disparities in obtaining cervical cancer screening.

Cervical Cancer Screening Disparities Experienced by Women with Disabilities

Relative to the number of studies examining disparities for women with disabilities in receiving screening mammography, there have been fewer studies examining women with disabilities' experiences in obtaining cervical cancer screening. Many of the available publications considered cervical cancer screening and breast cancer screening within the same study, which may have biased the participant selection towards including older women. This research demonstrates that cervical cancer screening disparities exist in groups of women experiencing limitations in their daily activity (e.g. Wei et al., 2006) and women with Intellectual, Developmental, or Learning Disabilities (e.g. Cobigo et al., 2013). While most researchers have found disparities in cervical cancer screening in women with disabilities, some researchers did not find a significant difference between women with disabilities and women

from the general population (e.g. Diab & Johnson, 2004). The potential reasons for these conflicting findings are explored within the section that describes these studies below.

Cervical cancer screening disparities experienced by women with limitations in daily activities.

Researchers frequently use limitations in daily activity, or requirement of equipment as criteria for inclusion of women in studies of those with a disability. Of the seven studies that have examined cervical cancer screening differences using this definition, five found significant differences in women with disabilities relative to the general population (Armour et al., 2009; Buckley et al., 2012; Drew & Short, 2010; Ramirez, Farmer, Grant, & Papachriston, 2005; Wei et al., 2006) and two did not (Diab & Johnson, 2004; Littman et al., 2012).

Wei et al. (2006) have found that women with disabilities were less likely to receive a Pap smear in the previous three years (OR=0.64, 95% CI 0.48-0.85). Using the same screening criterion, Ramirez et al. (2005) also reported that women with a disability are more likely to have not received a Pap smear in the study period (OR=1.17, 95% CI 1.05-1.31). In addition, Armour et al. (2009), Buckley et al. (2012) and Drew and Short (2010) all report that women with disabilities had significantly lower rates of cervical cancer screening tests, compared to the general population.

In contrast, Diab and Johnson (2004) and Littman et al. (2012) did not find significant differences between women with disabilities and women from the general population. Littman et al. and Diab and Johnson's criteria for being screened was having received a test in the previous three years, the same as studies that found a difference (Armour et al., 2009, Buckley et al., 2012, Ramirez et al., 2005, Wei et al, 2006). In addition, the criteria for disability used by

Littman et al. and Diab and Johnson were similar to the criteria used by authors who did find a difference. However, a potential reason for the lack of significant differences is the Littman et al. study is that it examined rates among women who were patients at a US Veteran's Administration Hospital, both with and without a documented disability, which means their sample may not have been representative of the general population of women. Similarly, in the Diab and Johnston study, rates were calculated in subgroups of women with different severities of disabilities rather than across women with any disability. Thus, the subgroups may not be representative of the more broad population of women with disabilities.

Despite the two studies reporting no differences, the majority of studies suggest that women with a limitation in the activities of daily living, one definition of disability, may face disparities in obtaining cervical cancer screening. The fact that significant differences in rates were found even when using these very broad definitions of disability suggests that if a more stringent criterion of disability is applied it is likely these disparities would be more pronounced.

Cervical cancer screening disparities experienced by women with Intellectual Disabilities.

While there is mixed evidence as to whether women with disabilities have lower cervical cancer screening rates, women with Intellectual Disabilities frequently been found to have lower rates. Haverkamp et al. (2004) and Reichard et al. (2011) both report that women with developmental disabilities or cognitive limitations in their cohorts were more likely to have never received a Pap smear (Haverkamp et al., relative risk=5.2, 95% CI 2.9-9.5), and more likely to have not received a Pap smear in the previous three years (Reichard et al., 2011, OR=2.02, 95% CI 1.60-2.54). In addition, Osborn et al. (2012) and Reynolds, Stanistreet, and Elton (2008) both report that women with Learning Disabilities in their studies were less likely

to have received a Pap smear in the previous three to five years (Osborn et al., incidence rate ratio = 0.54, 95% CI 0.53-0.57) or in the previous five years (Reynolds et al., OR=0.48, 95% CI 0.38-0.58). Cobigo et al. (2013) also reported that women with Intellectual or Developmental Disabilities were less likely to have received a Pap smear in the previous three years (OR=0.21, 95% CI 0.20-0.21). Finally, Haider et al. (2013) reported that women with Intellectual Disabilities had significantly lower rates of having received a Pap smear in the previous two years, (14.8%, 95% CI 10.3-20.8%), compared to women in the general population (71.1%, 95% CI 70.0-72.2%).

As this list suggests, there is consistent evidence across studies, samples and time frames that women with Intellectual Disabilities have lower screening rates for cervical cancer. Subgroups of women with Intellectual Disabilities have also been studied. These studies demonstrate that some subgroups have even lower cervical cancer screening mammography rates than the population of women with Intellectual Disabilities as a whole. Their findings indicate that this may relate to the healthcare and social support available to the women in these subgroups.

Factors related to cervical cancer screening in women with Intellectual Disabilities.

One possible reason for the decreased cervical cancer screening rates among women with Intellectual Disabilities is that these women face a lack of social support from their families for obtaining cervical cancer screening. Swaine et al. (2013) report that women living with family members, compared to women living in residential facilities, were less likely to receive cervical cancer screening tests (OR=0.21, 95% CI 0.08-0.52). In Taiwan, Lin et al. (2010) also report that women with Intellectual Disabilities who lived with their parents were also less likely to receive a cervical cancer screening test. This finding may be due to a greater availability of healthcare

providers. However, it may also be because family members hold negative attitudes about cervical cancer screening for women with Intellectual Disabilities or may feel they are unable to discuss the procedure with their family member or support their family member through the procedure.

Healthcare professionals also play a role in hindering access to cervical cancer screening. A study in the UK by Reynolds et al. (2008) revealed that women with Learning Disabilities were more likely to be removed from cervical cancer screening invitation lists by their general practitioner (OR=2.05, 95% CI 1.88-2.22). In the UK, women receive mailed invitations to obtain screening, and general practitioners review the invitation list to determine if they think any of their patients are ineligible for screening. According to the UK cervical screening programme, the only reasons for removing women from the list are when the women are older than 65 years or women who have received a full hysterectomy, regardless of whether the woman has a disability. The higher odds of women with Intellectual Disabilities being removed from the invitation list found in the study indicates that general practitioners may be incorrectly judging women with Learning Disabilities to be ineligible for screening.

One potential reason that general practitioners may not recommend cancer screening is because physicians or family members may assume women with Intellectual Disabilities are not sexually active (Swaine et al., 2013). Swaine et al. interviewed female family members (primarily mothers and sisters) of women with Intellectual Disabilities. Their participants reported that the main reason why their relative did not receive a Pap smear was because their relative was not sexually active. Similarly, Broughton and Thompson (2000) reported in their study of women with Learning Disabilities, that participants who were sexually active were significantly more likely to have received a Pap smear ($X^2=14.1$, $df=2$, $p<0.001$). In addition,

paid and family caregivers in the Broughton and Thompson study also reported that caregivers frequently assumed that the women in their care were not sexually active and thus did not need a Pap smear. Thus, these studies support the possibility that family members and caregivers of women with Intellectual Disabilities may assume that these women have never been sexually active, which may lead to them not promoting cervical cancer screening to women in their care.

An additional barrier that women with Intellectual Disabilities may face during a cervical cancer screening test, according to caregivers and family members is that the women feel anxious and stressed about the test, which can result in pain during the procedure (Broughton & Thompson, 2000; Swaine et al., 2013). Providing social support during the procedure, having the health professional explain the test beforehand, and having a female healthcare provider perform the test can all help make the test easier (Broughton & Thompson, Swaine et al., 2013). Biswas et al. (2005) attempted to raise the rate of cervical cancer screening among women with Learning Disabilities, and found that one-to-one counselling with a healthcare provider helped encourage women with Learning Disabilities to obtain a test. However, even with additional counselling, the rate of screening among women with Learning Disabilities in the Biswas et al. study was still less than the rate in the general population. One reason given by Biswas et al. is that even with additional counselling, many women and their caregivers were not interested in screening because women with Learning Disabilities reported not being sexually active, or their caregivers believed that the women are not sexually active.

In conclusion, significant differences in cervical cancer screening rates exist between women with disabilities and the general population. In particular, women with Intellectual Disabilities face significantly lower odds of receiving a cervical cancer screening test. One potential reason for this lower rate in women with Intellectual Disabilities is that it is frequently

difficult to establish whether women with Intellectual Disabilities have ever been sexually active. This difficulty points to the stigma surrounding sexuality in women with Intellectual Disabilities that still exists (McCarthy, 2000). Despite this stigma, there are steps that caregivers and health professionals can take to help facilitate cervical cancer screening in women with Intellectual Disabilities, such as by providing social support during the test. However, more qualitative research is needed to better understand the experiences of women with Intellectual Disabilities during cervical cancer screening, as well as how their family members perceive the women's sexual history, in order to fully understand how best to address these factors.

Colorectal Cancer Screening Disparities in Individuals with Disabilities.

Colorectal cancer screening has been even less widely studied in individuals with disabilities than cervical cancer screening, and frequently it is not the primary focus of the study. Typically, receipt of colorectal cancer screening is examined within a larger study examining preventive healthcare use in individuals with disabilities. In addition, there is some inconsistency as to the type of colorectal cancer screening modality examined. Some studies consider any type of colorectal cancer screening to be evidence of receipt of colorectal cancer screening. For example, an individual is counted as screened if they receive a fecal occult blood test in the past year or a colonoscopy or sigmoidoscopy in the past five to ten years. Other studies examine receipt of fecal occult blood tests and colonoscopies or sigmoidoscopies separately. In addition, some studies examine colorectal cancer screening in women only, while others examine colorectal cancer screening in both men and women. These are all considerations that do not necessarily apply to screening mammography and cervical cancer screening, and these factors can make it difficult to compare colorectal cancer screening with breast and cervical cancer screening.

Similar to breast and cervical cancer screening, some researchers considered participants to have a disability if they had any limitation in performing daily activities (Buckley et al., 2012; Diab & Johnston, 2004; Littman et al., 2012; Ramirez et al., 2005; Wei et al., 2006). Most studies using this definition have not found a significant difference in screening between individuals with disabilities and individuals from the general population (Buckley et al., Diab & Johnston, Littman et al., Ramirez et al.). Wei et al. published the only study to find a significant difference between groups. They report that women with disabilities were more likely to receive colorectal cancer screening (OR=1.37, 95% CI 1.08-1.73) relative to women in the general population. There were two differences between the Wei et al. study and the other studies. First, Wei et al. only included women, rather than both men and women. Second, Wei et al. defined screening as ever having received a colorectal cancer screening test, and did not specify a time interval for screening. Thus, these two differences in study approach may partially account for the significant findings in the Wei et al. study relative to others.

Among groups of individuals with Learning or Intellectual Disabilities, colorectal cancer screening is frequently examined as part of a larger study. Osborn et al. (2012) report that individuals with Learning Disabilities in their study were less likely to receive colorectal cancer screening (OR=0.84, 95% CI 0.77-0.92), while Haider et al. (2013) reported no significant difference in rates. A more recently published study (Ouellette-Kuntz, Coe, Cobigo, & Wilt, 2015) examined colorectal cancer screening rates among those with and without Intellectual and Developmental Disabilities, and reports significant differences in rates. Individuals with Intellectual and Developmental Disabilities in their study were less likely to have received an FOBT in the previous two years (adjusted OR=0.68, 95% CI 0.65-0.71) and were less likely to be up-to-date with colorectal cancer screening (adjusted OR=0.54, 95% CI 0.52-0.56), defined as

an FOBT in the previous two years, a flexible sigmoidoscopy in the previous five years, or a colonoscopy in the previous 10 years. Thus, while limited, there is increasing evidence that individuals with Intellectual Disabilities may face colorectal cancer screening disparities, similar to breast and cervical cancer screening.

This small set of studies provides some evidence of disparities in receipt of colorectal cancer screening. It is important to realize that there is a lack of research examining colorectal cancer screening rates, relative to the more extensive body of research examining breast and cervical cancer screening rates. Colorectal cancer screening has also not been recommended for healthy individuals for as long, and fewer resources have been used to persuade members of the public to obtain screening. This is reflected in the fact that colorectal cancer screening rates in the general population in the studies discussed in this chapter were frequently low. For example, the colorectal cancer screening rate in the general population in the Haider et al. (2013) study was 29.4%, and the rate in the Peytremann-Bridevaux, Voellin, and Santos-Eggimann (2008) study was 19.2%. In addition, in the Ouellette-Kuntz et al. (2015) study, only 26.4% of the general population had received an FOBT in the previous two years, and only 47.2% were up-to-date with colorectal cancer screening. Thus, one potential reason for the lack of significant differences is the lack of uptake of screening in the general population. If few people in the general population undergo screening, then a lower rate among individuals with disabilities is less likely to be significant.

A final problem is that frequently researchers grouped fecal occult blood testing and colonoscopies/sigmoidoscopies together, rather than examining rates separately. This is an issue because most studies were conducted in the US, and currently most American organizations recommend colonoscopies rather than fecal occult blood tests for asymptomatic individuals.

Colonoscopies are considerably more invasive than fecal occult blood tests, so it is possible that using these criteria for receipt of screening is partially contributing to the lower rates in the general population, as well as those with Intellectual Disabilities. There has been limited research examining fecal occult blood testing disparities among individuals with disabilities in Canada, where fecal occult blood testing is the main colorectal cancer screening test that is recommended, and where some provinces have introduced province-wide screening programs.

There is clearly more research needed to determine whether individuals with disabilities have lower rates of colorectal cancer screening, given that researchers have established that women with disabilities have lower rates of breast and cervical cancer screening, relative to the general population. There is also a need for research to determine if interventions to increase screening uptake, such as providing social support, can increase screening among people with disabilities, especially those with Intellectual Disabilities.

Chapter 4 Summary

The literature discussed in this section indicates that women with disabilities have lower screening mammography rates, compared to the general population, and may face additional barriers related to their disability. Women with disabilities may also experience disparities in cervical cancer screening, especially women with Intellectual Disabilities. In contrast, individuals with disabilities may be screened for colorectal cancer at the same rate as individuals in the general population, although the literature is small so further research is required to determine if screening rates are similar. Some of the qualitative findings suggest that it is also possible that the disparities women face in relation to breast and cervical cancer screening may be due to healthcare professionals' negative attitudes towards individuals with Intellectual Disabilities, especially in regards to cancer screening.

CHAPTER 5: Healthcare Professionals' Attitudes Regarding Individuals with Disabilities

Women with Intellectual Disabilities face breast and cervical cancer screening disparities (Cobigo et al., 2013), and there is also some evidence to suggest that individuals with Intellectual Disabilities also face colorectal cancer screening disparities (Ouellette-Kuntz et al., 2015). Although some of the disparities discussed may be explained by factors such as lower socioeconomic status, which may also apply to those without Intellectual Disabilities, factors related to disparities in the general population cannot explain the full extent of the disparities faced by those with Intellectual Disabilities. Some factors related to these disparities may be more closely associated with having a disability. For example, health professionals have told some family members of women with Intellectual Disabilities that breast and cervical cancer screening is not necessary for them (Llewellyn et al., 2011, Swaine et al., 2013), raising the possibility that health professionals' attitudes concerning individuals with disabilities are influencing whether they recommend cancer screening to these individuals.

This chapter will describe the extensive research examining health professionals' attitudes concerning individuals with disabilities, including Intellectual Disabilities. This literature provides evidence that health professionals' attitudes may be influencing their clinical behaviour, including whether they recommend cancer screening to individuals with disabilities. Before examining the research concerning health professionals' attitudes towards individuals with disabilities, the concept of attitudes and how attitudes are related to behaviour will be discussed in the section below, to place this research into context.

Definition of Attitudes

Attitudes may be defined as the tendency to like or dislike an object, or as the subjective evaluation of an object (Bohner & Dickel, 2011; Maio, Olson & Cheung, 2012). The object may be a concrete object, a controversial issue, specific individuals, or a group of people (Maio, Olson, & Cheung). For example, anyone may have attitudes toward vulnerable groups, such as people with Intellectual Disabilities (Schwartz & Armony-Sivan, 2001). Healthcare professionals may also have attitudes concerning behaviours such as screening cardiac patients for depression (Hart & Morris, 2008). Attitudes are relatively stable, but an individual may change his or her attitude when he or she receives new information. Attitude change requires the retrieval of past information about the target object, topic or person, then consideration of the new information along with the previous information. The result of this comparison may lead to a new attitude being developed by the individual (Bohner & Dickel, 2011).

The most common way for researchers to measure attitudes is through self-report (Hitlin & Pinkston, 2013). Often, a respondent is asked to rate their attitude on a numeric scale, with the number chosen corresponding to the intensity of the attitude (Bohner & Dickel, 2011). Some researchers judge attitudes to be uni-dimensional, and assume an attitude can be placed on a scale with a positive attitude at one end and a negative attitude at the opposite end (Maio, Olson, & Cheung, 2012). Other researchers describe a multidimensional model of attitudes that incorporates the possibility that an attitude may have a positive element and a negative element at the same time, which requires administration of several items to comprehensively measure the dimensions of the attitude (Maio, Olson & Cheung). Thus, some attitude scales discussed in this chapter produce a total score, indicative of positive attitudes or negative attitudes, while other

instruments incorporate multiple scores, to represent a multi-dimensional description of the attitude being measured.

Methods for assessing attitudes stem, in part, from the models that have evolved to describe these constructs. For example, one model which is frequently used is the expectancy-value model, based on Ajzen and Fishbein's (1977) Theory of Reasoned Action. They describe an attitude as being the sum of all of an individual's evaluative beliefs about an object, which indicates they see an attitude as multi-dimensional. According to them, an attitude can be described by four elements: action, target, context, and time. Their theory states that an individual's attitude can then directly influence whether he or she performs a behaviour. They also state that it is more likely that an attitude will influence a behaviour when the attitude elements and the behaviour elements correspond.

Theories such as this raise an important question as to whether attitudes predict, or are related to behaviour, or whether they are independent of behaviour. Ajzen and Fishbein (1977), and more recently, Kraus (1995), conducted systematic reviews of research exploring the relationship between attitudes and behaviour. Both Ajzen and Fishbein and later Kraus determined that in many studies attitudes are a strong predictor of behaviour, even after controlling for other factors. Ajzen and Fishbein report that, in studies exploring voting preference, individuals' attitudes about the electoral candidates predicted their voting behaviour. Kraus also found that studies examining many types of voluntary behaviour, such as church attendance, blood donation, and family planning, demonstrated a direct relationship between attitudes about the behaviour and performing the behaviour. Thus, the evidence to date suggests it is highly likely that attitudes about a group, such as individuals with Intellectual Disabilities, are related to behaviour, such as whether a primary care provider recommends cancer screening

to an individual with Intellectual Disabilities. It follows that understanding the relation between attitudes and behaviour may also help to explain disparities in rates of cancer screening.

Azjen and Fishbein (1977) developed the Theory of Reasoned Action based on their research. According to this theory, an individual's attitudes regarding a behaviour, and the individual's beliefs of what others think of the behaviour (subjective norms), influence the individual's intention to perform a behaviour, which is then directly related to whether the individual performs the behaviour in question. Ajzen (1991) later developed the Theory of Planned Behaviour, which has the components of the Theory of Reasoned Action with one addition: Ajzen also describes the perceived control the individual has over the behaviour as contributing to both the individual's intention to perform a behaviour, and performance of the behaviour itself. Ajzen considered this addition to better explain the variability in whether an individual's intention to perform a behaviour, and ultimately whether an individual performs the behaviour.

Other researchers have found that the Theory of Planned Behaviour, including the attitudes component, is useful in understanding healthcare providers' behaviour. It has been used to understand nurses' intention to provide smoking cessation advice (Puffer & Rashidian, 2004), nurses' assessment of pain (Nash et al., 1993), clinicians' intentions to screen cardiac patients for depression (Hart & Morris, 2008), and oncologists' and oncology nurses' intentions to screen cancer patients for depression (Breau, 2014). Thus, components of the Theory of Planned Behaviour, as described by Ajzen (1991), have been shown to be useful in understanding clinicians' behaviour.

In summary, research suggests that attitudes can be multidimensional and complex, as well as both positive and negative. They also appear to relate to how one acts, which indicates attitudes can impact others. Finally, attitudes appear to be open to change. This premise suggests that understanding attitudes is worthwhile, especially when they may have a negative impact on others, so that actions, such as education, can be taken to alter them and change the associated behaviour. Before doing so, however, it is important to have a good understanding of the attitudes in question, and of the behaviour they relate to. Accordingly, the following section reviews studies examining groups of students' and professionals' attitudes towards individuals with disabilities, including individuals with Intellectual Disabilities. Prior to the review of research, a description of the tools that have been developed to measure these attitudes is provided.

Scales Used to Measure Attitudes regarding Individuals with Intellectual Disabilities

Researchers have developed several self-administered questionnaires to measure individual's attitudes regarding people with disabilities, including Intellectual Disabilities. Two early scales to measure attitudes towards individuals with disabilities were developed by Antonak et al. in the 1960's, and are called the Attitudes Towards Disabled Persons Scale and the Scale of Attitudes Towards Disabled Persons. I do not discuss the psychometrics of these scales in detail, because the authors have not published data focused on their psychometric properties. In addition, these scales enquire regarding all disabilities and are not specific to Intellectual Disabilities. Finally, attitudes towards disabilities have changed considerably since the 1960's, given the influence of the disability rights movement on society to move away from institutionalization and towards community inclusion (Henry et al., 1996). Thus, these scales may not be as applicable in today's society as more recently developed scales.

The psychometrics of three of scales will be discussed in depth: The Mental Retardation Attitude Inventory-Revised (Antonak & Harth, 1994), the Community Living Attitudes Scale-Mental Retardation Version (Henry et al., 1996), and the Community Living Attitudes Scale-Mental Retardation Version Short Form (ten Klooster, Dannenberg, Taal, Burger, & Rasker, 2009). These scales were developed specifically to measure attitudes towards individuals with Intellectual Disabilities and are frequently used by researchers to measure different groups' attitudes towards them (e.g. Hampton & Xiao 2008; Ouellette-Kuntz, Burge, Henry, Bradley, & Leichner 2003; Ouellette-Kuntz et al., 2012). A detailed discussion of the development of these questionnaires, and their psychometrics, follows in the sections below. This is followed by a review of research examining the administration of these scales to different groups of students and health professionals.

Psychometrics of the Mental Retardation Attitude Inventory.

The first Intellectual Disability-specific scale to be published is the Mental Retardation Attitude Inventory. The original version of the Mental Retardation Attitude Inventory (MRAI) was developed by Harth in 1974 to measure students' and members of the public's attitudes towards individuals with Intellectual Disabilities. All of the items on the original fifty-item questionnaire were taken from Woodmansee and Cook's (1967) scale to measure the public's attitudes towards African Americans. Harth either replaced the wording of the item, or in some cases, rephrased the item in order to reflect situations that are more applicable. In his original 1974 study to assess the psychometrics of the MRAI, Harth had six special education experts review each item and comment on their applicability. Based on this pilot testing, minor revisions to some items were made.

The original MRAI (Harth, 1974) had five subscales: 1) the Integration-Segregation subscale, which measured respondents' beliefs regarding whether individuals with Intellectual Disabilities should be integrated into schools, communities, and workplaces, or whether they should be segregated from society; 2) the Overfavorableness subscale, which measured respondents' beliefs regarding characteristics that make individuals with Intellectual Disabilities superior to other individuals; 3) the Social Distance subscale, which measured respondents' willingness to recognize, live near, or associate with children with Intellectual Disabilities; 4) the Private Rights subscale, which measured respondents' endorsement of the view that landlords, school personnel, and others have the right to exclude individuals with Intellectual Disabilities from schools, communities, and the workplace; 5) the Subtle Derogatory Beliefs subscale, which measured the degree of respondents' degrading views regarding the moral character and social behaviour of individuals with Intellectual Disabilities. Each of the 5 MRAI subscales had 10 items, and the items were scored on a Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). After reverse scoring all items on the Subtle Derogatory Beliefs subscale, scores from these subscales were summed to create a total score.

Antonak and Harth revised the Mental Retardation Attitude Inventory (MRAI) in 1994, calling their revised scale the Mental Retardation Attitude Inventory-Revised (MRAI-R). They report that they revised their scale for two reasons. First, federal legislation introduced in the US after 1974 required integration of children with Intellectual Disabilities into public schools. This legislation meant that some of the original MRAI items concerning segregation in education were no longer applicable and should be removed or revised. Second, some of the items were judged to be unacceptably discriminatory and sexist. In total, 16 items were revised. This

resulted in a scale with 50 items, which had the original five subscales. Item scoring and subscale scores are calculated in the same way as for the original MRAI, but no total score is computed.

To assess the revised scale's psychometrics, Antonak and Harth administered the MRAI-R to 230 individuals, including 84 undergraduate students, 61 graduate students, and 85 professionals enrolled in continuing education programs or participating at professional conferences or seminars. The authors chose to sample from these populations because they expected the MRAI-R to primarily be administered to university students or professionals. Antonak and Harth also collected demographic information from participants, and information regarding: 1) whether the respondent knew someone with Intellectual Disabilities; 2) the frequency of the respondent's contact with individuals with Intellectual Disabilities; 3) the intensity of this contact; and 4) the respondents' general knowledge concerning Intellectual Disabilities. These data were gathered in order to determine if these characteristics were related to scores on the attitude scales.

Based on the results of preliminary analyses of items, Antonak and Harth (1994) removed 21 items from the new scale, including the entire Overfavorableness subscale due to redundancy with items on other subscales, as evidenced by higher than acceptable item correlations with total scores of subscales these items were not assigned to. In total, three items each were removed from the Integration-Segregation, Private Rights and Subtle Derogatory Beliefs subscales, and two items were removed from the Social Distance subscale. Each of these 11 items had low correlations with the appropriate subscale total or MRAI-R total score, high correlations with a different subscale score, or a factor loading below .345 on their assigned subscale.

As part of their evaluation of the MRAI-R, Antonak and Harth (1994) also conducted a principal axis factor analysis on the remaining 29 items to assess construct validity. Construct validity refers to whether an instrument is measuring what the researcher intends to measure (Polit, 2010). They found that the factor structure reflected the hypothesized four subscale structure of the MRAI-R. Most of the obliquely rotated factor loadings exceeded .345. The first factor accounted for 28.14% of the variance and consisted of seven of the eight original Social Distance subscale items. The second factor accounted for 14.32% of the variance and had five of the seven original Integration-Segregation subscale items. The third factor accounted for 9.88% of the variance and had five of the seven original Private Rights subscale items. The final factor accounted for 7.54% of the variance and had five of the seven original Subtle Derogatory Beliefs subscale items. Thus, Antonak and Harth considered these results to support the original subscale scores and the separation of the scale into four distinct subscales.

Antonak and Harth (1994) conducted a second principal components analysis to test their hypothesis that increased familiarity with individuals with Intellectual Disabilities would be related to more positive attitudes, as measured by the MRAI-R. Familiarity was measured by asking participants whether they had a friend, family member, or acquaintance with Intellectual Disabilities. They were also asked to rate the frequency and quality of their contact with individuals with Intellectual Disabilities, and their general knowledge about individuals with Intellectual Disabilities. They found a single familiarity factor accounting for 85.19% of the variance in responses, and the mean factor loading for items was .93. This result indicated a strong relationship between the MRAI-R items and respondents' measured familiarity with individuals with Intellectual Disabilities.

Antonak and Harth (1994) did not report on the internal reliability or the concurrent validity of the scale. Internal reliability refers to the consistency of the scale, that is, whether the observed responses are correlated with the true responses, while concurrent validity refers to whether an instrument's results are correlated with the responses to another instrument used to measure the same construct (Polit, 2010). However, Horner-Johnson et al. (2002) published data examining the internal reliability of a translation of the MRAI-R. These authors translated the MRAI-R into Japanese, and then back-translated the MRAI-R into English to establish semantic equivalence. Four Japanese researchers also read the English items of the MRAI-R in order to establish cultural equivalence of each item. As a result of their review, one MRAI-R item was removed because it was deemed to be culturally inappropriate.

After their translation, Horner-Johnson et al. (2002) administered their Japanese translation of the MRAI-R to 275 undergraduate students. A confirmatory factor analysis was significant, with 79% of the items having a factor loading of .30 or greater on their assigned subscale. These authors also conducted a series of correlations between the MRAI-R subscales and the subscales of the Community Living Attitudes Scale-Mental Retardation version (CLAS-MR; Henry et al., 1996) and found that the MRAI-R showed good concurrent validity with the CLAS-MR subscales. Horner-Johnson et al. concluded their translation of the MRAI-R was valid and reliable.

More recently, Hampton and Xiao (2008) assessed the psychometrics of a Chinese translation of the MRAI-R. Similarly to Horner-Johnson et al. (2002), they translated the MRAI-R from English into Chinese, and then back into English to determine the accuracy of the translation. Unlike the Horner-Johnson et al. study, cultural equivalence of the Chinese

translation of the MRAI-R was not established before examining the psychometric properties of their translated scale.

After translating the MRAI-R, Hampton and Xiao (2008) administered it to 534 university students specializing in either general education or special education. Their confirmatory factor analysis did not result in a good fit of items, indicating their data did not fit with Antonak and Harth's (1994) proposed four factor model. Hampton and Xiao suggest this may have been due to different cultural values between China and the US, and conclude that the MRAI-R may not be the most appropriate questionnaire to use in some cultures, in spite of Horner-Johnson et al.'s 2002 finding that the Japanese version of the MRAI-R is valid and reliable.

In summary, the authors of the MRAI-R report that the English-language version of the MRAI-R displays good construct validity (Antonak & Harth, 1994). Horner-Johnson et al. (2002) found that their Japanese translation of the MRAI-R exhibits good reliability and concurrent validity. In contrast, Hampton and Xiao (2008) found that a Chinese translation of the MRAI-R did not have acceptable construct validity. This difference in findings may indicate that the MRAI-R is not as reliable and valid when used in all non-Western cultures. It may also reflect the fact that Hampton and Xiao did not establish cultural equivalency before examining the psychometric properties of their translation. More research is needed to determine whether the MRAI-R has acceptable validity in cultures outside of the US. Further research by authors other than the scale creators would also provide stronger evidence for its validity and reliability. Given the limitations of the MRAI-R, other scales are worth consideration. One such scale is the Community Living Attitudes Scale-Mental Retardation version.

Psychometrics of Community Living Attitudes Scale-Mental Retardation Form.

The Community Living Attitudes Scale-Mental Retardation Form (CLAS-MR) was developed by Henry et al. (1996) based on the authors identifying a need for an instrument that measures respondents' attitudes towards social inclusion for individuals with Intellectual Disabilities. Henry et al. based 33 of the items in their original pool of 67 CLAS-MR items on a previous questionnaire, the Community Attitudes Toward Mental Illness Scale (Taylor & Dear, 1981). This scale measured respondents' attitudes towards the social inclusion of individuals with mental illness. Henry et al. revised Taylor and Dear's 33 items based on input from self-advocates with Intellectual Disabilities, and added 34 new items after interviewing and consulting with self-advocates with Intellectual Disabilities concerning their needs and their perception of how others view them. A sample of 67 items was generated and were placed on the questionnaire in random order, regardless of subscale, to minimize response bias. All items are scored on a six-point Likert scale, ranging from (1) strongly disagree to (6) strongly agree.

The CLAS-MR has four subscales: Empowerment, Similarity, Exclusion, and Sheltering. The Empowerment subscale measures respondents' views regarding whether people with Intellectual Disabilities should lead independent, fulfilling lives. Henry et al. explain that this subscale was most informed by input from self-advocates. The Similarity subscale measures respondents' beliefs regarding whether people with Intellectual Disabilities are similar to the respondents completing the questionnaire. The Exclusion subscale measures respondents' views regarding whether people with Intellectual Disabilities should be excluded from community life. The final subscale, Sheltering, measures respondents' views regarding whether people with Intellectual Disabilities are in need of additional protection from society, indicating that individuals with Intellectual Disabilities need to be segregated and excluded from community

life. Henry et al. (1996) state that they developed this subscale with the intention with it being less negative than the Exclusion subscale, because this subscale acknowledges that individuals with Intellectual Disabilities are a vulnerable population who may require additional supports.

Henry et al. (1996) administered CLAS-MR to 80 undergraduates and 203 community members. It was then administered twice to a second group of 104 undergraduate students, in order to assess the test-retest reliability of the scale. Test-retest reliability refers to an individual having similar responses to the same instrument on two or more separate occasions (Polit, 2010). The authors then conducted an exploratory principal components analysis to determine which items should be retained. A four factor Varimax rotated solution accounted for 36.1% of the variance in items. Forty-two of the 67 items had factor loadings of .4 or greater on one factor and lower than .4 on all other factors, indicating good specificity. This indicates that these items are strongly related to their subscale, but are not strongly related to other subscales. Henry et al. then calculated correlations between each item and its corresponding subscale. Forty items had correlations with their corresponding subscale of .3 or greater. Based on these analyses, 27 items from the original scale were omitted, and the final version of the CLAS-MR has 40 items: 13 items included in the Empowerment subscale, 12 in the Similarity subscale, 8 items in the Exclusion subscale, and 7 items in the Sheltering subscale.

The 40-item CLAS-MR was then administered to 355 staff members from 81 agencies whose clientele consisted primarily of people with Intellectual Disabilities. Henry et al. (1996) conducted a confirmatory factor analysis to assess the construct validity and found that the four factor model of the CLAS-MR was a good fit: the adjusted goodness-of-fit index was .92 and the root mean square residual was .09. In addition, all 40 items had significant factor loadings of .31 or greater, in the appropriate direction, to their corresponding subscale, with most factor loadings

falling in the .4-.7 range. This secondary analysis supports the subscale structure of the CLAS-MR and is evidence of good construct validity.

Henry et al. (1996) also determined the internal reliability and concurrent validity of the 40-item CLAS-MR using Cronbach's alpha, which refers to the variability of individual items and how this variability relates to the total scores (Polit, 2010). A Cronbach's alpha of .70 to 0.75 is acceptable and Cronbach's alphas of 0.80 and above are considered desirable (Polit, 2010). All four subscales had Cronbach's alphas of .7 or greater, indicating that the items were internally reliable; that they are related to the subscale to which they were assigned. In addition, subscales of the CLAS-MR correlated moderately (Pearson r 's between .31-.87) and in the appropriate direction with subscales of the Scale of Attitudes Toward Disabled Persons (Antonak et al., 1982), a questionnaire that measures respondents' non-specific attitudes towards individuals with many types of disabilities. This provides evidence that the two scales measure a similar construct and supports the concurrent validity of the CLAS-MR. Thus, based on these analyses the authors conclude that the CLAS-MR is reasonably reliable and valid.

Horner-Johnson et al. (2002) also assessed the psychometrics of a Japanese translation of the CLAS-MR in their study that included the MRAI-R. The CLAS-MR was translated into Japanese and then back-translated into English, in order to establish semantic equivalence. The CLAS-MR was also reviewed by a panel of experts to determine cultural equivalence. The experts determined one item was culturally irrelevant and it was subsequently deleted. Horner-Johnson et al. conducted a confirmatory factor analysis and found that the four factor structure of the CLAS-MR is appropriate. The factor analysis was significant, with items loading onto four factors, and 87% of items having a factor loading of .30 or greater on the appropriate subscale. They also found that the subscales of the CLAS-MR correlated with the corresponding subscales

of the MRAI-R, with correlation coefficients ranging from .3 - .6, supporting the concurrent validity of the CLAS-MR.

In addition to the 40-item CLAS-MR that Henry et al. (1996) developed, a shorter, 17-item CLAS-MR has also been developed and used in Canada (Jones, Ouellette-Kntz, Vilela, & Brown, 2008; Ouellette-Kuntz et al., 2012; Ouellette-Kuntz et al., 2003), and the Netherlands (ten Klooster et al., 2009). While Henry et al. developed the shorter version of the CLAS-MR, only ten Klooster et al. have examined the psychometrics of this shorter version. Two of the authors of this study translated the CLAS-MR short form into Dutch. This translation was then pilot tested with a group of 10 nursing students (the intended sample population) and ten Klooster et al. report that these students had few to no problems in completing their translated version of the scale. Analyses to examine internal reliability indicated the Exclusion and Similarity subscales had Cronbach's alphas above .7, an acceptable level (Polit, 2010). The Empowerment subscale had a lower Cronbach's alpha of .64. Ten Klooster et al. report that this was sufficiently high for exploratory purposes. However, the Sheltering subscale was found to have low internal reliability, even when some items were deleted. Subscales of the CLAS-MR short form were significantly, but moderately, correlated (Pearson r of .56-.59) with the appropriate subscales of the Attitudes Towards Disabled Persons-Form A Scale (Yuker, Block, & Campbell, 1960) and Scale of Attitudes Towards Disabled Persons Scale (Antonak, 1982), providing some evidence of concurrent validity. One exception was the Sheltering subscale. It did not correlate significantly with any other subscales from the other disability scales. Thus, results regarding the concurrent validity of the scale are mixed, with certain subscales of the CLAS-MR short form being more valid and reliable than others.

In summary, the CLAS-MR was developed by Henry et al. (1996) with greater involvement of self-advocates with Intellectual Disabilities than used by the developers of the MRAI (Harth, 1974) or MRAI-R (Antonak & Harth, 1994). Psychometric analyses by the scale's authors indicate that the CLAS-MR has good content validity, and in a subsequent study exploring the psychometrics of a Japanese version of the CLAS-MR, it also demonstrated good construct validity (Horner-Johnson et al., 2002). A Dutch translation of the CLAS-MR short form demonstrated lower reliability and concurrent validity (ten Klooster et al., 2009) than the original version. While Ouellette-Kuntz et al. (2003) used the English language version of the CLAS-MR, they did not report data concerning the psychometric properties of the English language short form are less valid and reliable relative to the original questionnaire, this may be due to the CLAS-MR not being culturally or linguistically appropriate for countries outside of the US. It may also be due to ten Klooster et al. choosing to use the CLAS-MR 17-item short form rather than the full, previously published 40-item CLAS-MR (Henry et al., Horner-Johnson et al.). Given that attitudes towards individuals with Intellectual Disabilities are multi-faceted and complex, it is possible that by removing some of the 40 CLAS-MR full version items, ten Klooster et al. failed to capture as wide of a scope of attitudes, resulting in a less effective representation of respondents' attitudes. In addition, ten Klooster et al. do not describe the process for removing items. It is possible that some of the items removed were best retained. Had they used the results of a factor analysis to remove items based on their relation to the full scale and other items, they may have had a shorter version of the CLAS-MR which better represents the full CLAS-MR.

More research is needed to explore the applicability of the CLAS-MR in countries outside of the US, and more research is needed to explore the psychometrics of the short form of

the CLAS-MR. However, at this time, the full CLAS-MR does exhibit good preliminary psychometric properties. It also was developed with input from self-advocates, which adds to its content validity, and it has been used more recently than the MRAI-R. This is important, because attitudes towards individuals with disabilities have changed over the past few decades, in part due to the discontinuation of institutions and the adoption of a community living approach (Henry et al., 1996). In addition to studies examining the psychometrics of these scales, many studies exploring university students', support staff's, and health professionals' attitudes toward individuals with Intellectual Disabilities have been conducted using the MRAI-R or the CLAS-MR or CLAS-MR short form. The results of these studies, and difference in attitudes within subgroups of the samples used in these studies, are explored in the next section.

The Effects of Gender on Attitudes Regarding Individuals with Intellectual Disabilities

Three of the four studies that have investigated the relationship between gender and attitudes towards individuals with Intellectual Disabilities found differences between men and women. In Ouellette-Kuntz et al.'s (2003) study of Canadian senior psychiatry residents, a series of Analyses of Variances (ANOVAs) on the scales from the short form of the CLAS-MR was conducted. Male residents scored significantly higher on the Exclusion subscale ($M = 4.60$, $SD=0.74$ vs. $M = 4.35$, $SD=0.63$) indicating males have more negative attitudes. Female residents scored significantly higher on the Similarity subscale ($M = 5.49$, $SD=0.46$ vs. $M = 5.13$, $SD=0.69$), also indicating males had more negative attitudes. Finally, female residents' mean Sheltering subscale score was also higher than males' ($M = 3.87$, $SD=0.74$ vs. $M = 3.41$, $SD=0.73$), also indicating more negative beliefs were held by the male residents. Taken together, the results indicate that that male residents are more likely to believe individuals with Intellectual Disabilities should be excluded from community life, while female residents are more likely to

consider individuals with Intellectual Disabilities to be similar to themselves, and are more likely to believe that individuals with Intellectual Disabilities are a vulnerable group that should have additional protection.

Also in Canada, Jones et al.'s (2008) study included the short form of the CLAS-MR to measure attitudes among support staff from 27 community agencies for clients with Intellectual Disabilities (Male $n = 51$; Female $n = 190$). A series of t-tests revealed that men scored lower on the Similarity subscale than women ($M = 5.37$, $SD=0.77$ vs. $M = 5.63$, $SD =0.73$), but higher on the Exclusion ($M = 1.65$, $SD=0.95$ vs. $M = 1.25$, $SD=0.56$) and Sheltering subscales than women ($M = 3.02$, $SD=0.94$ vs. $M = 2.60$, $SD=1.13$). These findings indicate that male respondents more strongly believed that they are not similar to individuals with Intellectual Disabilities and that individuals with Intellectual Disabilities should be excluded from community life. In contrast to the Ouellette-Kuntz et al. (2003) results, males in this study felt more strongly than females that individuals with Intellectual Disabilities require additional protection.

Interestingly, in general the participants in the Jones et al. (2008) study had more positive attitudes according to their CLAS-MR scores than those in the Ouellette-Kuntz et al. study (2003). It is possible that this reflects the differing experiences of the two samples, with those in the Ouellette-Kuntz et al. study having interacted with more individuals with psychiatric illnesses in addition to their Intellectual Disability. However, it is also possible the relatively more positive attitude in the Jones et al. study simply reflects greater exposure to individuals with Intellectual Disabilities as a whole, as they were working in the field, while the Ouellette-Kuntz et al. participants were still in training. As discussed in the following sections, researchers have found that having personal or professional experience with people with disabilities increases positive attitudes towards people with disabilities in general.

In a third study that examined gender differences in attitudes, Sahin and Akyol (2010) administered the Turkish Attitudes Toward Disabled Persons Scale (Dokmen, 2000) to 148 nursing students and 381 medical students. This scale assesses attitudes towards individuals with any type of disability, rather than attitudes towards individuals with Intellectual Disabilities specifically. It includes 30 items on three subscales: the Compassion subscale, which enquires about communication and interaction with the people with disabilities; the Social Values subscale, which measures the respondent's attitudes towards social and workplace integration of people with disabilities; and the Resource Distribution subscale, which measures attitudes about the contribution of individuals with disabilities to society. All items are scored on five-point Likert scales, with the anchors (1) strongly agree and (5) strongly disagree. The items from each subscale are then summed to produce a total score. Sahin and Akyol report that a series of t-tests demonstrated that female nursing students and female medical students had significantly higher total scores ($M = 122.59$, $SD = 14.73$) than male students ($M = 117.92$, $SD = 15.44$), indicating that female students were more likely to report that they felt individuals with disabilities are similar to themselves. Thus, among participants in this study female students had more positive attitudes, relative to males.

Finally, Coyle, Saunderson, & Freeman's (2004) study of 140 dental students and 78 social policy students did not find an overall difference in attitudes by gender, but did report some differences in secondary analyses. Coyle et al. administered modified versions of the Dental Student Attitudes to the Handicapped Scale (Lee & Sonis, 1983) and the Scale of Attitudes Towards Disabled Persons (Yuker et al., 1960) to their participants. Coyle et al. (2004) found that there was no difference in total scores for either scale among the participants due to gender. However, t-tests did reveal significant differences by gender for some items. Female dental

students had more positive attitudes on two items concerning community inclusion. They also had more negative attitudes than male students on two items regarding clinical interaction with people with Intellectual Disabilities. Coyle et al. interpret these as scattered results, suggesting that males and females express both negative and positive attitudes, with these varying based on the aspect of beliefs being examined.

These results, however, should be interpreted with some caution. Coyle et al. (2004) modified some items on each scale, as well as changed the wording on the questionnaires from “the disabled” to “individuals with learning disabilities”. The authors do not report that they conducted analyses to ensure their adapted scales were valid and reliable. Thus, it is possible that the changes made did affect the results. It is also important to note that the items on both scales are summed to create one total score each. This means that attitudes were measured as more uni-dimensional constructs than in other studies where scales with multiple subscales were used. For example, studies using the CLAS-MR did find gender effects, albeit they varied by subscale. Thus, it is possible that this phenomenon was not captured by the total scores provided by the scales that Coyle et al. used.

In summary, of the four studies that have examined the effect of gender on attitudes towards individuals with Intellectual Disabilities, most found a difference by gender, with female respondents generally having more positive attitudes (Jones et al., 2008; Ouellette-Kuntz et al., 2003; Sahin & Akyol et al., 2009). Despite these differences, one study (Coyle et al. 2004) did not find any total scale score differences by gender, and female participants in the Ouellette-Kuntz et al. study were more likely to endorse items on the CLAS-MR stating that individuals with Intellectual Disabilities require additional protection. Although it is possible to interpret the belief that a specific group requires additional protection as a positive attitude Ouellette-Kuntz et

al., 2012), the developers of the CLAS-MR, Henry et al. (1996), interpreted this scale as reflecting a negative attitude. Thus, based on this small literature, it appears that females frequently, although not always, hold more positive attitudes towards people with disabilities.

The Effects of Age on Attitudes Regarding Individuals with Disabilities

Only two groups of researchers have examined whether age is related to attitudes towards people with various types of disabilities, including Intellectual Disabilities. Dorji and Solomon (2009) administered a Chinese translation of the Scale of Attitudes Towards Disabled Persons (SADP; Chan, Jua, Ju, & Lam, 1984) to 170 nurses and physicians, who had a mean age of 33.4 years. Through a series of Spearman's rho correlations they found that older participants had lower scores on the misconception subscale of the SADP, indicating they had more misconceptions about people with disabilities than younger participants. There were no significant differences by age for the other SADP subscales.

The second study found in the literature reports different results. Matziou et al. (2009) administered the Attitudes Towards Disabled Persons Scale (ATDP; Yuker, 1960) to nurses and nursing students, and compared differences in ATDP total scores by age, gender, and professional status (student or professional). Matziou et al. did not explore the relationship between age and ATDP scores in nursing students, because this group had a narrow age range. They did investigate the effect of age within subgroups of nursing professionals based on gender, and report that they chose to look within gender-based subgroups because they found that gender was significantly related to scores. The authors found no relationship (no significant correlations) between age and ATDP scores within both the male and female nurse professional subgroups. One possible reason for this result differing from that of Dorji and Solomon et al. could be that the participants had a higher mean age. The mean age of participants in the Dorji

and Solomon study was 33.4 years (SD=8.03) while the mean age of participants in the Matziou et al. study was 24.6 years (SD=9.3). Because Dorji and Solomon also did not examine age independently of gender, it is also possible that gender was not evenly distributed among their sample by age, resulting in a possible confound between age and gender.

These results suggest that there may be differences in attitudes towards people with disabilities that vary by age. However, the results are not conclusive. Also, no studies could be found that examined the effect of age using Intellectual Disabilities specific attitudes scales. It is likely that most studies have not investigated the effect of age because they have sampled primarily from university students, or have had limited age ranges, making it difficult to evaluate the true effect of age on attitudes. The tendency to use these groups of health professionals or of health professionals in training has, however, allowed researchers to explore the effects of being in specific professions or different programs on attitudes and several studies have used Intellectual Disability specific scales.

Effects of University Program of Study and Profession in Attitudes Regarding Individuals with Disabilities

In many studies that administered attitudes questionnaires to university students, the type of program the students were enrolled in was related to participants' attitudes towards people with disabilities. Schwartz and Armony-Sivan (2001), Boyle et al. (2010), Coyle et al. (2004), Horner-Johnson et al. (2002), Hampton & Xiao (2008), and ten Klooster et al. (2009) all found differences due to participants' degree program. Au and Mann (2006) also found differences by profession and professional degree in their study of health professionals and health professional students.

Frequently, health professional students were shown to have more positive attitudes towards people with disabilities, including Intellectual Disabilities, than students in other professions. For example, Schwartz and Armony-Sivan (2001) administered a Hebrew translation of the CLAS-MR to 43 social work students, 42 natural sciences students, 24 law students, and 40 social sciences students. A multivariate analysis of variance (MANOVA) revealed that law students had more negative attitudes about individuals with Intellectual Disabilities than those studying social work. Specifically, social work students scored lower on the Exclusion subscale, ($M = 2.11$, $SD=0.50$) than law students ($M = 2.86$, $SD=0.96$), and higher on the Similarity subscale ($M = 4.60$, $SD=0.56$ and $M = 4.14$, $SD=0.71$). This finding indicates that social work students are less likely to hold the attitude that individuals with Intellectual Disabilities should be excluded from community life, and are more likely to consider individuals with Intellectual Disabilities to be similar to themselves. This may relate to the likelihood that social work students may have had relatively more experience with people with Intellectual Disabilities than law students either in their personal life or as part of their training.

Horner-Johnson et al. (2002) also found that students in health-related programs had more positive attitudes towards people with Intellectual Disabilities. These researchers administered a Japanese translation of the CLAS-MR (Horner-Johnson et al.), MRAI-R (Horner-Johnson et al.), the Scale of Attitudes Towards Mental Retardation and Eugenics (Horner-Johnson et al.), and the Marlowe-Crowne Social Desirability Scale-Short Form (Horner-Johnson et al.) to 286 undergraduate students in a variety of disciplines, including social work, psychology, engineering, physical sciences, and economics.

Horner-Johnson et al. (2002) report that, in their study, students majoring in mental health had more positive attitudes regarding individuals with Intellectual Disabilities than those

studying the physical sciences, economics, or engineering. A MANOVA revealed that students in psychology and social work had lower scores on the Exclusion subscale of the CLAS-MR ($M = 1.62$, $SD = 0.38$), relative to students in the physical sciences and economics ($M = 2.00$, $SD=0.61$), and engineering ($M = 2.23$, $SD = 0.85$). Thus, the psychology and social work students were less likely to hold the attitude that individuals with Intellectual Disabilities should be excluded from community life. Psychology and social work students also had lower scores on the CLAS-MR Sheltering subscale ($M = 3.03$, $SD=0.47$) and higher scores on the CLAS-MR Similarity subscale ($M = 4.18$, $SD=0.41$) than students who did not declare a major ($M = 3.38$, $SD=0.44$ for Sheltering, $M = 3.78$, $SD=0.63$ for Similarity). This latter finding suggests that psychology and social work students are also more likely to consider individuals with Intellectual Disabilities to be similar to themselves, and less likely to think that individuals with Intellectual Disabilities should be protected from society, than students who had not indicated they intended to go into those fields.

In a separate MANOVA, Horner-Johnson et al. (2002) also found that students in a psychology and social work group had higher scores on the Integration-Segregation ($M = 3.63$, $SD=0.46$), Social Distance ($M= 3.99$, $SD=0.65$), and Subtle Derogatory Beliefs ($M = 3.50$, $SD=0.40$) subscales of the MRAI-R, than students in their engineering group (Integration-Segregation: $M = 3.29$, $SD = 0.48$; Social Distance: $M = 3.46$, $SD=0.74$; Subtle Derogatory Beliefs: $M = 3.09$, $SD=0.58$), a physical sciences and economics group (Integration-Segregation: $M = 3.21$, $SD = 0.68$; Social Distance: $M = 3.33$, $SD=0.86$; Subtle Derogatory Beliefs: $M = 3.22$, $SD=0.57$), and a group of students with no declared major (Integration-Segregation: $M = 3.18$, $SD = 0.63$; Social Distance: $M = 3.28$, $SD=0.82$; Subtle Derogatory Beliefs: $M = 3.07$, $SD=0.59$). Higher scores on all subscales indicates more positive attitudes.

Thus, Horner-Johnson et al.'s (2002) set of results indicates that students in the psychology and social work groups held fewer beliefs supporting segregation of individuals with disabilities, felt that individuals with disabilities are more similar to themselves and held fewer negative attitudes towards individuals with disabilities. This provides evidence that psychology and social work students have more positive attitudes towards individuals with Intellectual Disabilities than students who are not currently planning a career in an allied health profession.

In yet another study, nursing students were found to have more positive attitudes than their friends who were not in a nursing program. Ten Klooster et al. (2009) administered Dutch translations of the Attitudes Toward Disabled Persons Scale-Form A (a version of the ATDP-A, ten Klooster et al.), the Scale of Attitudes Toward Disabled Persons (ten Klooster et al.), and the CLAS-MR (ten Klooster et al.) short form to 81 nursing students and 48 age-matched peers who were not in a nursing program. T-tests indicated nursing students had higher mean total scores on both the ATDP-A ($M = 115.03$, $SD = 17.47$ vs. $M = 103.56$, $SD = 19.43$, respectively) and the SADP ($M = 111.87$, $SD = 15.49$ vs. $M = 100.47$, $SD = 19.12$), indicating they considered individuals with various disabilities to be more similar to individuals without disabilities, and that they also had more positive attitudes about individuals with various disabilities than their non-nursing peers. Nursing students also had higher mean scores on the Similarity subscale ($M = 4.89$, $SD = 0.75$ vs. $M = 4.52$, $SD = 0.95$) and the Empowerment subscale ($M = 4.12$, $SD = 0.75$ vs. $M = 3.71$, $SD = 0.79$) of the CLAS-MR short form. This means that the nursing students were more likely to perceive individuals with Intellectual Disabilities to be similar to themselves, and to have positive attitudes towards empowerment of individuals with Intellectual Disabilities than their same-age peers who are not in a nursing program. There were no significant

differences between nursing students and their peers for mean scores on the Exclusion and Sheltering subscales of the CLAS-MR.

As with the previous studies by Schwartz and Armony-Sivan (2001) and Horner-Johnson et al. (2002), these results suggest that those in health professional programs may hold more positive attitudes towards those with disabilities than those in other university programs. Pre-existing attitudes towards individuals with Intellectual Disabilities may influence choice of program. Therefore, it is possible that health related programs attract individuals who are more likely to hold positive attitudes towards those with disabilities. It is also possible that experience with people with Intellectual Disabilities as part of their clinical training, or education about this population that is received during a program can contribute to attitudes towards individuals with Intellectual Disabilities.

Another study examined two groups of students as well, but provides less clear results because the group enrolled in a clinical program did not show more positive results. Coyle et al. (2010) found that social policy students had more positive attitudes towards individuals with disabilities than dental students. They administered 24 attitudinal items taken from the Dental Student Attitude to the Handicapped Scale (Lee & Sonis, 1983) and the Scale of Attitudes to Disabled Persons (Yuker, 1960) to 140 dental students and 78 social policy students. Using a t-test, the authors discovered a significantly lower mean total attitude score for dental students ($M = 86.7$, 95% CI = 85.1-88.4) than for social policy students ($M = 95.3$, 95% CI = 93.0-97.5) indicating social policy students had more positive attitudes about individuals with various disabilities than dental students. Coyle et al. describe this as a potential problem, because dental students are required in the UK (where this study took place) to provide care to all members of the public, including individuals with disabilities. Caution should be taken when considering the

results of this study, however, because the researchers utilized a selection of individual items taken from scales instead of full scales that had established psychometrics.

Coyle et al.'s (2004) results also raise the question of whether differences may exist between groups of participants who fall within the general category of being in health related program Boyle et al. (2010) conducted a study that included only health professional students and found differences in attitudes by type of health profession being studied. They administered the Medical Condition Regard Scale (Christison et al., 2002), which measures attitudes towards people with Intellectual Disabilities, substance abuse, and acute mental illness, to health professional students. Coyle et al.'s sample included 249 emergency health (paramedic) students, 458 nursing students, 86 midwifery students, 169 occupational therapy students, 236 physiotherapy students, and 98 health science students. They report that on the section on Intellectual Disabilities, physiotherapy students had fewer positive attitudes toward individuals with Intellectual Disabilities ($M = 51.10$, $SD=8.77$) relative to students in emergency health ($M = 53.88$, $SD=9.41$), midwifery ($M = 53.51$, $SD=10.17$) and health sciences ($M = 55.31$, $SD=8.98$) The authors suggest the differences by profession could be due to how students in different professions view their roles in treating individuals with Intellectual Disabilities. For example, individuals training in some professions may perceive themselves as being more likely to have patients with Intellectual Disabilities and this may contribute to more positive attitudes towards the group.

In a second study that also included only participants who were in a health profession or studying a health profession, Au and Mann (2006) found that there were differences in attitudes by type of profession. They administered the Attitude Toward Disabled Persons scale (Yuker, 1960) to 511 students in occupational therapy, physiotherapy, nursing, and social work. The

authors report that occupational therapy students had the most positive attitudes ($M = 70.58$, $SD=12.73$) and social work students had the least positive attitudes ($M = 64.59$, $SD=10.48$). Au and Mann suggest that this finding could be due to their data also indicating that, relative to other disciplines, social work students reported having lower levels of knowledge about disabilities. This highlights the fact that the role of prior experience with individuals with disabilities should also be considered when examining differences among participants who are in different training programs.

In a final study focussed solely on health profession students, Tervo, Palmer, and Redinius (2004) administered the Attitude Toward Disabled Persons Scale (Antonak & Livneh, 1988), the Scale of Attitudes Towards Disabled Persons (Antonak, 1981), and the Rehabilitation Situations Inventory (Dunn et al., 1992) to 141 nursing students, 46 medical students, and 51 other health professional students (occupational therapy, physiotherapy, speech pathology and auditory students, and psychology students). They conducted a series of analyses of variance (ANOVAs) and post-hoc t-tests, and found that nursing students had more negative attitudes towards individuals with various disabilities than other health professional students. Specifically, nursing students had lower total scores on the SADP, and lower scores on the Optimism-human rights subscale of the SADP, and had more behavioural misconceptions about individuals with disabilities, as evidenced by student responses to items in the Rehabilitation Situations Inventory.

Together, this collection of studies points to differences in attitudes towards individuals with disabilities that vary by program of study. When standardized instruments are administered to both health professional and non-health professional undergraduate students, health professional students generally have more positive attitudes towards individuals with disabilities (Coyle et al., 2004) and individuals with Intellectual Disabilities (Horner-Johnson et al., 2002; Schwartz and

Armony-Sivan 2001; ten Klooster et al., 2009), and view individuals with Intellectual Disabilities to be more similar to themselves (Horner-Johnson et al.; Schwartz and Armony-Sivan.; ten Klooster et al.). When instruments are administered to health professional students only, there are differences by type of health profession. One reason for this finding could be that health professional students, and certain groups of health professional students, view their role in caring for individuals with disabilities in different ways (Boyle et al., 2010), and some may believe they are more likely to care for patients with disabilities, which may also impact their views. Across these studies, it is not possible to discern whether students' experiences and characteristics prior to entering their program of study has an effect on their views, and whether this experience influences their choice of profession. It is, however, also possible that the amount of education and experience regarding those with Intellectual Disabilities that students are exposed to varies among programs within the general field of health care. However, as the following section describes, it is likely that prior experience does contribute to forming attitudes both prior to training and during training.

The Effects of Previous Experience with Individuals with Disabilities on Attitudes Regarding Individuals with Disabilities

Many of the studies examining attitudes of health profession students towards people with disabilities were conducted with pre-clinical or first year students. This suggests that it is unlikely that the students would have had much professional experience with individuals with disabilities at the time they participated in the research. This raises the question as to whether students' prior experiences are actually the primary contributing to the differences found. Four studies have investigated the effects of experience with individuals with disabilities on attitudes towards them expressed by students and add some insight to this.

In addition to finding differences in attitudes by type of program, ten Klooster et al. (2009) found that attitudes varied by previous personal experience with individuals with disabilities. Personal experience with people with disabilities was defined in that study as having a friend, family member or acquaintance with disabilities. In a multiple linear regression, ten Klooster et al. found that having a friend or relative with a physical disability was predictive of having a more positive attitude towards people with physical disabilities, as measured by the Attitude Toward Disabled Persons Scale (ten Klooster et al.) and Scale of Attitudes Towards Disabled Persons (ten Klooster et al.). The results also revealed that having a friend or relative with an Intellectual Disability was not predictive of having a higher score on subscales of the CLAS-MR, and thus more positive attitudes. This is an intriguing result because it shows that previous experience had a different effect depending on the type of disability in question; physical or Intellectual.

A second study that included students was conducted by Sahin and Akyol (2010). They also found that respondents' personal experience with individuals with disabilities was related to their attitudes about individuals with disabilities in general. They administered a Turkish translation of the Attitudes Toward Disabled Persons (Dokmen, 2000) scale to 147 nursing students and 381 medical students. Sahin and Akyol also asked participants about their previous experience with individuals with disabilities. The authors report that higher total scale score and subscale scores, indicating more positive attitudes, were found for respondents who reported previous close contact with individuals with disabilities.

Two additional studies report differences in attitudes due to whether respondents had previous professional, rather than personal, experience with patients with disabilities (Ouellette-Kuntz et al., 2012; Tervo et al., 2004). Professional experience was defined as having had one or

more patients with a disability or by the number of patients with disabilities that the participants had worked with.

In the first study, Tervo et al. (2004) administered the Attitude Toward Disabled Persons Scale (Antona & Livenh 1988), the Scale of Attitudes Towards Disabled Persons (Antonak, 1981), and the Rehabilitation Situations Inventory (Dunn, Umlauf, & Mermis, 1992) to 141 nursing students, 46 medical students, and 51 other health professional students (occupational therapy, physiotherapy, speech pathology and auditory students, and psychology students). They found that having more years of previous professional experience with individuals with disabilities, and having more hours in this employment, were predictive of having higher scores on the Rehabilitation Situations Inventory (Dunn et al., 1992). This indicates that individuals with more previous experience were more comfortable with patients with disabilities displaying challenging behaviour towards health professionals.

In the second study, Ouellette-Kuntz et al. (2012) administered the CLAS-MR short form to 258 medical clerks. They report that medical clerks who had clinical experience with patients with Intellectual Disabilities received higher Sheltering subscale scores on the CLAS-MR, indicating that these participants felt that individuals with Intellectual Disabilities are in need of greater protection. Respondents who had seen patients with Intellectual Disabilities had a mean Sheltering subscale score of 3.27 (SD=0.69), compared to a mean Sheltering subscale score of 3.07 (SD=0.64) for respondents who did not report seeing any patients with Intellectual Disabilities. Ouellette-Kuntz et al. argue that their finding is positive, because it indicates that medical clerks realize that individuals with Intellectual Disabilities are vulnerable. However, this opinion is in contrast to that of Henry et al. (1996), who developed the scale, who posited that

higher scores on the Sheltering subscale indicate more negative attitudes towards individuals with Intellectual Disabilities.

Only four studies were found that examined the effect of experience interacting with individuals with disabilities, whether personally or in a professional capacity, had an effect on respondents' attitudes as measured by questionnaires. Three found that prior experience was associated with more positive attitudes, although in one study this only applied to individuals with physical disabilities, not to those with Intellectual Disabilities (ten Klooster et al., 2009). The fourth study found that those with more experience with individuals with Intellectual Disabilities were felt more strongly that they are in need of protection (Ouellete-Kuntz et al., 2012). This was interpreted as a positive attitude by the authors, but would have been perceived as a negative attitude by the developer of the CLAS-MR, which was used in the study. These studies used different scales and recruited different groups of health profession students, which may underlie some of the variability found. In addition, the nature of health professional training and exposure to people with disabilities may vary by country. Nevertheless, the results generally suggest that greater exposure does lead to more positive attitudes. It is important to remember, however, that certain professions may experience different levels of interaction with patients with disabilities as part of their training, which also may impact results when they are asked to complete questionnaires regarding attitudes. More research, especially based on qualitative methodologies, is needed to understand these complex relationships.

Chapter 5 Summary

This chapter provided an overview of the literature regarding the measurement of attitudes towards individuals with disabilities. Several standardized questionnaires have been developed in the past three decades and used to examine individuals' attitudes regarding people with

disabilities. Doing so, researchers have found that four factors may be related to individuals' attitudes towards people with disabilities: gender, age, type of degree or profession, and previous personal and professional experience with people with disabilities, including Intellectual Disabilities.

The small body of research at this time suggest that women have more positive attitudes. This may relate to gender roles, with women being more protective of individuals with disabilities, including Intellectual Disabilities. Age may also be an important factor. However, the results are equivocal at this time. Only two studies could be found that included age as part of their analyses. This dearth of data is likely due to the limited age ranges among participants in most studies. The research described also points to participants' type of degree or profession is an important consideration. Health professional students appear to have more favourable attitudes than non-health professional students. Differences among type of health professionals and health professional students have also been found. These may be related to the different roles of health professionals in caring for individuals with disabilities. Alternatively, it could also be due to differences in the amount or quality of clinical experience with individuals with disabilities. Previous experience with people with disabilities also appears to be a key factor in influencing attitudes about individuals with disabilities in general, and is interrelated with discipline. Overall, the current literature is not decisive, but does indicate that several factors may play a role in health care students' and professionals' attitudes towards individuals with disabilities, and with Intellectual Disabilities in particular.

Summary of Literature Review

This research is being conducted based on the assumption that cancer screening is beneficial and that members of the general population, including individuals with disabilities,

should receive cancer screening. Screening for breast, cervical, and colorectal cancer is currently recommended by many government bodies and professional organizations, including the British Columbia Cancer Agency (BCCA, 2016). Breast cancer is detected through screening mammograms, cervical cancer is detected through cervical cytology testing and human papilloma virus (HPV) testing, and colorectal cancer is detected through fecal occult blood testing and flexible sigmoidoscopies and colonoscopies. Recently, a study by Miller et al. (2014) questioned the efficacy of screening mammography among women in the general population, although other studies still demonstrate the benefits of regular screening mammography, and the majority of health organizations continue to recommend this form of screening to average-risk women aged fifty years and older.

Thus, as the literature reviewed indicates, many organizations and health agencies recommend cancer screening to members of the general public. The age ranges and recommended interval between screenings vary by type of cancer screening (breast, cervical, and colorectal). Therefore, for this study, I will use the British Columbia Cancer Agency (BCCA) recommendations, because the current study is conducted in British Columbia. Within Canada, health professionals follow the guidelines issued by their province's health agency. In addition, in spite of the recent controversy in the media regarding whether women of any age should receive screening mammograms, I will assume that women should still receive mammograms, given that no government body, including the BCCA, has changed their recommendations regarding screening mammography in light of the Miller et al. (2014) study. The BCCA also does not differentiate between individuals with Intellectual Disabilities and the general public. This means that all individuals with Intellectual Disabilities at average risk of developing cancer should be provided with cancer screening as recommended by the BCCA guidelines.

While cancer screening is still recommended, certain groups of individuals have lower rates of cancer screening. For example, among members of the general population, disparities in screening exist by ethnicity (breast and colorectal), socioeconomic status (breast and cervical), access to health professionals (breast, cervical, and colorectal), and family situation (breast). Some of these factors are interrelated: for example, socioeconomic status is related to access to health professionals, especially in countries that lack public healthcare systems. This is because individuals with higher incomes are more likely to be able to afford private health insurance and thus access health professionals. While there have been special health promotion programs to increase cancer screening among certain groups, significant disparities still remain.

One group of individuals who consistently report lower rates of cancer screening are individuals with disabilities, including Intellectual Disabilities. Some of these disparities may be explained by factors related to screening in the general population: for example, individuals with disabilities frequently experience lower socioeconomic status. However, other factors contributing to the disparities experienced by individuals with disabilities are directly related to their disability. For example, women with physical disabilities may face difficulty accessing screening mammograms because the clinics conducting the screening may not be accessible. In addition, women with disabilities, including Intellectual Disabilities, may receive care from health professionals who have negative attitudes regarding women with disabilities and thus do not recommend screening. Researchers interviewing women with physical and Intellectual Disabilities have reported that health professionals explained to them (women with disabilities) that screening mammography and cervical cancer screening are not necessary for women with disabilities. In addition, research has shown that women with Intellectual Disabilities are less likely to be invited to attend cervical cancer screening, presumably because their health

professionals judge them to be ineligible for screening. Thus, there is converging support for the possibility that health professionals' attitudes concerning individuals with Intellectual Disabilities may be one factor related to whether they recommend cancer screening to their patients with Intellectual Disabilities.

Studies in the general population have determined that one of the key factors influencing whether women obtain breast and cervical cancer screening is primary care providers' recommendation for cancer screening. For example, among women who had an appointment with their general practitioner but did not receive a Pap smear (cervical cancer screening test), 86% said it was because their physician did not recommend a Pap smear (Coughlin et al., 2005). In addition, in a study of a cohort of women who received screening mammograms, Stockwell et al. (2003) explored whether these women received colorectal cancer screening tests. Stockwell et al. report that 93% of the women who received a sigmoidoscopy or colonoscopy had received a recommendation from their physician. Thus, measuring primary care providers' recommendation for cancer screening is a logical proxy for whether individuals actually receive screening.

The aim of the present study was to explore the factors related to primary care providers' recommendations for cancer screening to individuals with Intellectual Disabilities. In addition, the present study describes family physicians and family practice residents' experiences recommending cancer screening to their patients with Intellectual Disabilities. This was done to further explore which factors, including attitudes, are related to cancer screening recommendations. It was hoped that these data would help place the findings of the quantitative component of the study into the larger clinical care context.

Despite this small body of research exploring attitudes towards people with disabilities, including Intellectual Disabilities, and the inclusion of health professionals and health professional students in many of the studies, no study to date has explored whether attitudes towards people with Intellectual Disabilities are related to health professionals' provision of care to patients with Intellectual Disabilities, such as a recommendation for cancer screening. People with Intellectual Disabilities are no less entitled to the best possible healthcare than any other group in our society. It is essential to understand whether health professionals' care of this vulnerable group is influenced by factors that do not enter into their decision-making with other patients. The research discussed has shown that many health professionals may hold negative attitudes towards people with Intellectual Disabilities, and that some characteristics, such as age, gender, program of study and previous experience may contribute to professionals' negative attitudes. For this reason, it is important to understand both whether attitudes may be a factor in health professionals' provision of care and whether there are specific characteristics among health professionals that contribute to more negative or positive attitudes. Studies have demonstrated that specialized training and experience can influence health professionals' attitudes. Thus it is important to determine whether attitudes are related to clinical behaviour and decision making in relation to cancer screening to help determine whether training and experience are warranted to improve access to screening for this medically underserved group.

CHAPTER 6: Methods

No study to date has examined whether primary care providers' and primary care provider students' attitudes about individuals with Intellectual Disabilities are related to clinical practice, such as their recommendation for cancer screening. In addition, there have been very few studies (McIlfatrick et al., 2011 being one exception) that have explored primary care providers' experiences regarding recommending cancer screening for individuals with Intellectual Disabilities. The current study employed a parallel, convergent mixed-method design. First, an initial cross-sectional survey phase documented primary care providers' and primary care provider students' attitudes about individuals with Intellectual Disabilities in general, and whether these attitudes were related to their anticipated likelihood of recommending cancer screening to hypothetical patients with Intellectual Disabilities presented in written vignettes. Second, an exploratory, qualitative phase consisted of descriptive, open-ended interviews with family physicians and family practice residents in order to gain insight into their experiences recommending cancer screening to individuals with Intellectual Disabilities. I discuss the rationale for employing a mixed methods design in the section below.

Rationale for Study Design

A mixed methods study design was chosen for two reasons. First, it was felt that the quantitative survey developed a hypothetical scenario, and the results of this phase may not be immediately transferable to the real world context. Second, while the quantitative phase examined one factor, attitudes towards people with Intellectual Disabilities, and its contribution to clinicians recommending cancer screening, it was considered likely that other factors contribute to clinicians' decision to recommend or not recommend cancer screening to patients with Intellectual Disabilities. Thus, the aim of conducting a qualitative phase within a mixed

methods design was to help place the quantitative findings in the clinical context, and to examine other potential factors related to primary care providers' decision to recommend cancer screening.

This mixed methods design is best described as a convergent design. The two phases of the study were conducted in parallel and independently of each other, and were only merged at the interpretation step of the research. While the phases were conducted sequentially, with the data collection for the quantitative phase being complete prior to data collection in the qualitative phase commencing, this was mainly due to difficulties in participant recruitment for the qualitative phase. The data analysis step for each phase took place independently and concurrently, and the phases only converged in the final interpretation step, presented in Chapter 9.

Given the convergent nature of the mixed methods design, it was decided that a pragmatic paradigm was best suited for the current study. According to Cresswell and Plano Clark (2011), a pragmatic paradigm is most often used as the theoretical framework for convergent mixed methods designs. This paradigm is focused on the research problem, and has a real world practical orientation. Thus, the paradigm is consistent with the overall aim of both phases of the research study: to better understand the experiences of primary care providers' recommending cancer screening to patients with Intellectual Disabilities.

Given that the study phases were conducted sequentially and in parallel, the methods for each phase are presented separately, first for the quantitative phase and then the qualitative phase. These methods include descriptions of each phase's participants, study instruments, data

collection procedures, and planned analyses. The ethical approval process, which constituted a single Research Ethics Board application for both phases, is presented in a subsequent section.

Quantitative Phase Research Methods

In this section, I first review the research questions and hypotheses for the quantitative phase. I then describe this phase's participants, and the instruments used to collect data. Next, I describe the data collection steps, including participant recruitment and the study procedures, before outlining the data analysis plan for this phase.

Research questions and hypotheses.

The overarching research question for both phases of this study was: how do primary care providers recommend cancer screening to their patients with Intellectual Disabilities? The specific primary research question for the quantitative phase was: Are attitudes concerning individuals with Intellectual Disabilities in general related to participants' anticipated likelihood of recommending cancer screening to hypothetical patients with Intellectual Disabilities presented in fictional vignettes? Accordingly, the research hypothesis for the quantitative phase was: primary care providers and primary care provider students with more positive attitudes concerning individuals with Intellectual Disabilities will report a higher likelihood of recommending cancer screening to hypothetical patients with Intellectual Disabilities, relative to primary care providers and students with more negative attitudes.

Participants.

Two groups of primary care provider trainees were recruited for the quantitative phase. All family practice residents associated with the University of British Columbia (UBC) in Vancouver, British Columbia (BC), Canada were invited to participate. All nurse practitioner

students enrolled at three universities across BC were also invited to participate. At the time of the study, there were 154 residents in the family practice program and approximately 90 nurse practitioner students enrolled in the three nurse practitioner programs. The family practice residency at UBC is 24 full-time months, and there are 15 practice sites at health centres across BC, including urban, rural, and remote sites. Once physicians complete the residency and write licensing examinations, they become board-certified family physicians. The nurse practitioner program is a full-time two-year program and includes coursework and practical work. Graduates of these programs may register as Nurse Practitioners in BC after taking the licensure examinations.

In addition, family physicians practicing within BC were recruited through their provincial professional organization. The BC College of Physicians and Surgeons is the regulatory body for physicians across BC. The BC College of Physicians and Surgeons published a 2015 medical directory for all physicians licensed to practice in BC, and this directory was obtained by the author from the College. There were no email addresses for physicians listed in this directory, thus the decision was made to mail paper copies of the survey to physicians. Given that there are approximately 6,000 family physicians registered with the BC College of Physicians and Surgeons, it was not feasible to send surveys to all family physicians in BC. Instead, a random sample of 670 registered family physicians was generated and all physicians in this sample were mailed surveys.

Instruments.

A demographic form developed specifically for the study was administered to participants prior to their completing other measures. The two primary instruments that were used for the survey portion of the study were: 1) the Community Living Attitudes Scale-

Intellectual Disabilities version (CLAS-ID, Henry et al., 1996), which measures attitudes about individuals with Intellectual Disabilities; and 2) a series of written vignettes developed for the current study. The vignettes presented hypothetical patients meeting criteria to be screened. Participants were asked to rate the likelihood that they would anticipate recommending cancer screening for each patient. All instruments are included in Appendix A.

Demographics form.

Two versions of the demographics form were developed for use in this study, one for residents and students and a separate form for physicians. Both forms solicited basic personal information, such as the participant's profession (nurse practitioner student, family practice resident, family physician, or nurse practitioner). The form then questioned the participant regarding their gender (male, female, or other) and age (ages were grouped in categories to help prevent inadvertently identifying participants). Next, the participants were asked to respond to several questions regarding their training and experience with individuals with Intellectual Disabilities. First, the participant was asked whether they had any training specific to working with people with Intellectual Disabilities (yes or no, and if yes asked to specify type of training). Participants were then asked if they have any friends or family members who have Intellectual Disabilities (yes/no) and if yes, they were asked to briefly describe the nature of the relationship.

A separate demographic form was used for family physicians. In addition to the questions put to all participants, questions regarding the participant's professional practice were included. First, participants were asked how many years they had practiced in their current profession (0-5 years, 6-10 years, 11-15 years, 16-20 years, more than 20 years). The participants were then asked how many patients with Intellectual Disabilities they typically see over a year (0-3 patients, 4-8 patients, 9-15 patients, and more than 15 patients). Small ranges were chosen for

these categories, because previous research indicates that primary care providers typically devote a small portion of their practice to individuals with Intellectual Disabilities. Finally, participants were asked whether they consider their practice to have a significant portion devoted to patients with Intellectual Disabilities. They could respond: “yes, definitely”; “yes, somewhat”, “no, most of my patients do not have Intellectual Disabilities”; or “I do not have patients with Intellectual Disabilities as part of my practice”. Categories were used for some variables, first to help prevent inadvertently identifying participants, and also because it was anticipated that for some questions concerning experience and workload, it would be easier for participants to answer a categorical question rather than an open-ended question.

The Community Living Attitudes Scale-Intellectual Disabilities version.

The Community Living Attitudes Scale-Intellectual Disabilities version (CLAS-ID) was developed by Henry et al. (1996) to measure university students’ and professionals’ attitudes towards community inclusion for individuals with Intellectual Disabilities. It was originally published as the Community Living Attitudes Scale-Mental Retardation version (CLAS-MR), but has since been renamed the CLAS-ID. All uses of the phrase “mental retardation” in the scale have been replaced with the phrase “intellectual disabilities.” The development of the CLAS-ID was discussed in detail in Chapter 5 and is summarized briefly below. I received permission to use the scale from the CLAS-ID first author, Dr. David Henry (personal communication, July 2014).

The CLAS-ID has four subscales. The Similarity subscale measures respondents’ attitudes concerning how individuals with Intellectual Disabilities are similar to themselves. The Empowerment subscale measures respondents’ attitudes regarding empowerment in individuals with Intellectual Disabilities. The Sheltering subscale measures respondents’ beliefs that

individuals with Intellectual Disabilities are vulnerable and in need of special protection. The Exclusion subscale measures respondents' attitudes regarding segregating individuals with Intellectual Disabilities from social life. Henry et al. (1996) considered a higher score on the first two subscales to indicate more positive attitudes towards individuals with Intellectual Disabilities and a higher score on the last two subscales to indicate more negative attitudes towards individuals with Intellectual Disabilities.

Henry et al. (1996) based 33 of the items of the original pool of 67 CLAS-ID items (then called the CLAS-MR) on a previous questionnaire, the Community Attitudes Toward Mental Illness Scale (Taylor & Dear, 1981), which measured respondents' attitudes towards the social inclusion of individuals with mental illness. Henry et al. revised the 33 items from the Community Attitudes Toward Mental Illness Scale based on input from self-advocates with Intellectual Disabilities, making them the only researchers to develop a tool to measure attitudes regarding people with disabilities to include consultation with individuals with disabilities as part of the scale development. They also added 34 new items after interviewing and consulting with self-advocates with Intellectual Disabilities concerning their needs, and considering self-advocates' views of the public's perception of Intellectual Disabilities. Based on this research, Henry et al. generated a sample of 67 items.

Henry et al. (1996) administered the 67-item CLAS-MR to a group of undergraduate students and community members, and then to a second group of undergraduate students, in order to confirm the four factor structure of the CLAS-MR and also to evaluate its validity and reliability. This team of researchers reduced the number of items of the CLAS-MR to 40, based on these statistical analyses. The authors then administered the 40-item CLAS-MR to a large

sample of staff from community living agencies, and confirmed the four factor structure of the CLAS-MR, and also the scale's internal reliability and construct validity.

There are 40 items in total on the CLAS-MR, now called the CLAS-ID: 12 items on the Similarity subscale, 13 items on the Empowerment subscale, 7 items on the Sheltering subscale, and 8 items on the Exclusion subscale. All items are scored on a six-point Likert scale, ranging from (1) Strongly disagree to (6) Strongly agree. Half of the items are negatively worded, so that a higher score on the item indicates a more negative attitude. Half the items are then reverse coded so that a higher score for all items on each subscale are in the same direction, positive or negative, depending on the subscale in question. Subscale items are then summed to create a total subscale score. Typically, a total score is not produced. Instead the subscale scores are treated as individual variables. All four subscale scores are then divided by the number of items in each subscale in order to create a standardized subscale score that ranges from 1-6.

A definition of Intellectual Disabilities was not provided in the covering material, including the demographics form, or in the preface to the CLAS-ID. This decision was made for two reasons. First, previous researchers using the CLAS-ID did not include such a definition in their surveys. Second, it was reasoned that providing a definition might bias participants' responses. It is possible that participants may have considered other disabilities, such as cognitive impairment due to stroke, as an Intellectual Disability. As detailed later in the dissertation, the qualitative phase interview guide prompted participants to define Intellectual Disabilities in order to determine whether participants are aware of the most commonly used criteria for determining if an individual has an Intellectual Disability.

Cancer screening vignettes.

A series of eight vignettes was developed by the author to measure primary care providers' likelihood of recommending cancer screening to hypothetical patients with Intellectual Disabilities and hypothetical patients with other health conditions. These vignettes were developed based on BC Cancer Agency guidelines for cancer screening and were pilot tested along with the other study instruments. Clinical vignettes have been demonstrated to be as reliable and valid as actors portraying patients in studies examining physicians' clinical practices (Dresselhaus et al., 2004; Peabody et al., 2000; Peabody et al., 2004). Clinical vignettes are also more reliable and valid, and less time consuming, than abstracting information from patients' medical charts. Vignettes have been used to assess general practitioners' recommendations for preventive screenings (Dresselhaus et al., 2004) and for providing general medical care to patients (Peabody et al., 2000; Peabody et al., 2004).

In this study, four vignettes portrayed individuals with Intellectual Disabilities, and four vignettes portrayed individuals with a chronic health condition, for a total of eight vignettes. The four patients with a chronic health condition served as controls in the event that participants had negative attitudes concerning a specific type of screening. For the vignettes portraying individuals with Intellectual Disabilities, one presented a female patient in need of a screening mammogram, one presented a female patient in need of a cervical cancer screening test, one presented a female patient in need of a colorectal cancer screening test, and one presented a male patient in need of a colorectal cancer screening test. Vignettes 1, 3, 5, and 7 portray patients with Intellectual Disabilities, and vignettes 2, 4, 6, and 8 portray patients with chronic health conditions.

The vignettes for the patients with chronic illness presented the same information as the vignettes for the patients with an Intellectual Disability. For example, the reason for the medical visit was the same, regardless of whether the individual was described as having an Intellectual Disability or not. Specifically, in vignettes 1 and 2 (breast cancer screening), the reason for the visit was a skin condition diagnosed as eczema; in vignettes 3 and 4 (cervical cancer screening), the reason for the visit was to obtain a prescription for acne treatment; for vignettes 5 and 6 (colorectal cancer screening in women), the purpose of the visit was an annual health check-up; for vignettes 7 and 8 (colorectal cancer screening in men), the purpose of the visit was to obtain advice before beginning an exercise program. All hypothetical patients met the age criteria for the specific type of cancer screening, and when asked, all patients reported never having received the type of cancer screening specified, making them eligible for screening. The reason for female and male patients being presented separately is because only women may undergo mammograms and cervical cancer screening tests. Thus, by presenting male and female patients in need of colorectal cancer screening separately, the effect of sex of the patient could be examined separately from the colorectal cancer screening recommendation. At the end of each vignette, the participants were asked to rate the likelihood that he or she anticipated recommending the type of cancer screening to the hypothetical patient on a scale ranging from 0 (very unlikely) to 10 (very likely).

Internal consistency.

To examine the internal consistency of CLAS-ID scores, Cronbach's alpha was computed for each subscale using the data gathered in the quantitative phase of the current study. The Cronbach's alpha for the CLAS-ID Empowerment (0.79), Exclusion (0.79), and Similarity (0.70) subscales fell at or above 0.7, a level which is generally accepted as showing acceptable internal

consistency (Pollant, 2013). However, the overall Cronbach's alpha for the Sheltering subscale was 0.67, indicating it had relatively lower internal reliability. Examination of scores revealed that all items on three of the scales (Empowerment, Exclusion, and Similarity) had positive item-total correlations, and the subscale Cronbach's alpha remained close to the original level when any specific item was removed. Notably, this was also true for the Sheltering subscale. The Cronbach's alpha was reduced when each item was removed, indicating the scale is more reliable if all items are retained. This suggests that the relatively low internal reliability is not due to the subscale containing an item that it should not. However, it may suggest that additional items could improve the ability of that subscale to reflect the construct of Sheltering. It is important to note that previous researchers have also found that the Sheltering subscale is the least reliable of all the CLAS-ID subscales. This may reflect the debate in the literature as to whether the Sheltering subscale reflects positive or negative attitudes. While the scale's creators intended to this subscale to measure negative attitudes (Henry et al., 1996), other researchers posit that this subscale reflects positive attitudes (Ouellette-Kuntz et al., 2012). Accordingly, in the generation of hypotheses for this study, I did not propose a hypothesis for the effect of the Sheltering subscale on anticipated likelihood of recommending cancer screening.

Most subscales had the highest reliability when all items were included, and the item-correlations for most subscales were positive and contributed to the subscale's internal reliability. In contrast, some item-total correlations on the Similarity subscale were negative. In addition, the Similarity subscale Cronbach's alpha increased to .81 when item 9 was removed, suggesting this item may be reducing the Similarity subscale's overall internal consistency. Given that the CLAS-ID has been previously published, item 9 was still included in the overall

CLAS-ID analysis. However, some caution should be taken in interpreting the results regarding the Similarity subscale scale in this sample.

Data collection.

Pilot testing of instruments.

The instruments for the survey study phase were pilot tested prior to recruiting participants for the study. Four graduate students in different disciplines were asked to complete the CLAS-ID and vignette questions. I recruited the graduate students by sending an email on Green-Chat asking for volunteers and offering a small incentive (cookies). Green-Chat is the email address list for Green College, a graduate residence at UBC. One aim of this pilot testing was to determine the duration needed for completion of the instruments. An additional aim was to evaluate whether the vignettes were unclear or required revision for ease of reading. Although the CLAS-ID has been extensively pilot tested, it was also pilot tested with this sample to determine completion time and also to determine readability. Completion of all of the survey instruments, including time to review the consenting information, was approximately fifteen minutes.

Participant recruitment.

Nurse practitioner students at three different universities in BC were invited to participate in the survey by asking administrative staff to circulate a summary of the study and the electronic link to the survey by email, either in the body of an email or as part of an electronic newsletter. Nurse practitioner students at UBC were also recruited by posting a poster at the UBC School of Nursing that described the study and provided the author's contact information. Approximately 90 nurse practitioners were invited to participate including students at all three schools.

Family practice residents in the UBC Family Practice residency were also recruited. Approximately 154 residents are enrolled in the program at any given time. Family practice residents are physicians who undertake an additional two years of general medical practice and write licensing examinations in order to be board-certified family physicians. In this study, family practice residents at UBC were recruited by having administrative staff email a description of the study and electronic link to the survey to the UBC family practice residency email list. A reminder email was distributed a couple of weeks after the initial email. This request required prior approval from the UBC Faculty of Medicine Research Access Committee.

A random sample of family physicians practicing in BC was mailed a paper version of the survey and a self-addressed, postage paid return envelope. The sample, composed of approximately 11% of family physicians registered with the BC College of Physicians and Surgeons, was selected by using the Microsoft Excel random number generator to randomly assign ID numbers to all family physicians listed in the College directory. All physicians randomly assigned a number between 1 and 670 were included in the sample. Because some physicians in the sample did not have a BC address listed, or did not provide a mailing address to the College' directory, additional physicians were selected, without replacement, in a similar manner to the method used to select the initial sample to achieve a pool of 670 potential participants.

Procedure.

Residents and nurse practitioner students submitted their responses electronically. Recruitment of residents and nurse practitioner students took place in February and March 2015. Physicians who participated returned paper copies of the survey in self-addressed, stamped

envelopes via regular mail. Surveys were distributed between February and May 2015. The deadline for receipt of surveys included in the final analyses was June 30, 2015.

Data analysis.

A Priori power analyses

Previous studies using the CLAS-ID and other attitude measures were used to estimate the minimum samples required for the planned analyses. Previous studies have reported response rates of 79-92% in studies exploring attitudes about people with Intellectual Disabilities that included medical students (Ouellette-Kuntz et al., 2012; Tervo et al., 2002), 83% in a study including nursing and medical students (Tervo et al., 2004;) and 41-70% in studies including community support staff (Jones et al., 2008, Rose et al., 2012). Based on these, a potential sample size of 222 was expected. Specifically, it was expected that 77 residents (50% response rate among 154 residents), 45 nurse practitioner students (50% response rate among 90 students), and 100 family physicians (15% response rate among a sample of 670 physicians) would respond. It was not possible to estimate how many Nurse Practitioners would respond because no previous study has included this group. Because of this, this subgroup was not included in determinations of potential sample size. Overall, because so few studies were available to show a consistent pattern of response rates, a very conservative estimate of response rate was set at 15% for physicians. Thus, a sample of approximately 100 participants was judged to be realistic, and would provide a sufficiently large sample size for the planned analyses even in the event that family practice residents, nurse practitioners, and nurse practitioner students did not reply to the survey.

In addition to recruiting physicians, residents and nurse practitioner students were invited to participate for three reasons. First, the majority of research using validated questionnaires to explore attitudes towards individuals with Intellectual Disabilities has been conducted with university students. Thus, in order to meaningfully compare the results of the survey to previous research, a similar population needed to be surveyed. Second, the response rate among university students, including medical residents, is generally higher than response rates among professionals. Thus, students were recruited in the present study because it was also believed this would increase the sample size. Although, the response rate between physicians and nurse practitioner students was similar in this study; the response rate among residents was higher, which suggests this strategy was somewhat successful. Finally, previous research has shown experience with individuals with Intellectual Disabilities prior to health professional training is the main factor influencing attitudes towards individuals with Intellectual Disabilities. Therefore, it was felt that the clinical experience held by professionals alone would be unlikely to account for differences in attitudes among participants, justifying the recruitment of student participants who would be future professionals.

In total, 108 responses to the survey were received. Of physicians, 28 family residents associated with UBC (18% response rate) and 71 family physicians practicing in the community (11% response rate) replied to the survey (combined 12% physician response rate). This was within the 15% minimal rate expected. Some response rates for trainees were lower than expected. In total, 28 residents (18% response rate) and 9 nurse practitioner students (10% response rate) responded to the survey. However, together, the trainee response rate was 15%, also within the minimal rate set. The relatively low response rate of students, compared to previous research, may have been due to having administrative staff email residents and students

the link to the survey, while previous studies may have had faculty distribute their surveys. Another potential reason for the lower than anticipated response rate is that the survey was distributed electronically, rather than distributing a paper version. A further reason could be that, due to challenges associated with distributing an electronic survey, no monetary incentive was offered. Both factors have been shown to be associated with lower response rates to surveys (Dillman et al., 2013). For students and residents, multiple attempts at recruiting participants were made, and it was thought that by including self-addressed envelopes and sending paper copies of the questionnaire would encourage physicians to return the completed questionnaires. Given that no information was gathered on non-respondents, it is not known if respondents were representative of the larger population

Planned descriptive and inferential analyses.

A total of 108 surveys were completed, including 37 electronic responses from residents and nurse practitioner students, and 71 paper surveys from physicians that were returned by mail. Of these paper surveys, two were returned uncompleted, with a note that the physician did not complete the survey because he or she works solely in administration. Therefore, the sample consisted of 106 participants; 37 students or residents (34.9%) and 69 professionals (65.1%). Of the students and residents, nine were nurse practitioner students (8.5% of the total sample) and 28 were family practice residents (26.4% of the total sample). Of the 69 professionals, four did not self-identify as family physicians, instead they identified as “other” and described themselves as either emergency physicians (n=2) or hospitalists (n=2). These four physicians were included in the analysis, because: (1) according to the College medical directory, they were listed as family physicians, and (2) inspection of their CLAS-ID scores and cancer vignette scores indicated their scores were not outliers.

The survey data were examined for entry errors and missing data. Of the 106 who returned completed questionnaires, 2 participants were missing data for all 40 CLAS-ID items, and one participant was missing data for 20 of 40 CLAS-ID items and all of the cancer screening vignette scores. One participant was missing data for all of the cancer screening vignette scores. These four participants were excluded from further analysis, leading to a total of 102 participants. The remaining participants had less than 20% of CLAS-ID data missing. In addition, each of the 40 CLAS-ID items had less than 15% of data missing. If a participant did not reply to an individual item, the mean score for that item for all participants was entered and used for calculating the participant's subscale scores. Data reflecting the participants who were missing an acceptably low number of items and had their individual item scores replaced is given in Table 1.

Table 1: Details of Missing CLAS-ID Values for Participants (N = 102)

Participant	1	3	7	11	12	13	18	27	32	33	34	35	36	37	38	39	40
P334	X	X	X			X											
P253		X															
S37		X															
S6				X					X	X	X	X	X	X			
S1					X		X										
S34				X													
S16								X									
P045															X	X	X

After reverse coding appropriate items, all item scores were summed to create the four subscale scores, as described by Henry et al. (1996). The summed subscale scores were then divided by the total number of items in the subscale (13 for Empowerment, 8 for Exclusion, 7 for Sheltering, and 12 for Similarity) in order to produce subscale scores ranging from 1 to 6.

I conducted the preliminary descriptive analysis, including calculating either means and standard deviations or frequency counts and percentages, for each demographic variable, and for the questions regarding participants' experiences with people with Intellectual Disabilities and, for physicians, questions regarding their medical practice. A series of chi-square tests of independence was conducted to determine whether age, gender, professional status (resident/student versus physician) and experience were interrelated.

I also conducted the preliminary descriptive analysis, including means and standard deviations, for each CLAS-ID subscale score. Distributions of non-dichotomous variables were then examined for skewedness, kurtosis, and outliers. When appropriate, outliers were removed and/or variables were dichotomized. This resulted in removal of the data for 9 participants' who had one or more CLAS-ID subscale scores that were judged to be outliers (i.e. scores were more than 1.5 interquartile ranges above or below the median). CLAS-ID data was considerably less skewed and kurtotic once these scores were removed. Cronbach's alpha was used to explore the internal consistency of the data for the final sample of 95. Alpha was set at .05 for all subsequent analyses.

Next, preliminary analyses were done to examine whether demographic and experience characteristics were related to CLAS-ID subscale scores. Multivariate Analyses of Variance (MANOVAs) were conducted to determine if participant gender, age (5 categories), previous personal experience (yes/no) and previous work experience with people with Intellectual Disabilities, (yes/no) were related to CLAS-ID subscale scores. A Multivariate Analysis of Covariance (MANCOVA) was then used to determine whether professional status (student/resident vs. professional) was related to CLAS-ID subscale scores. Age was included as a co-variate for

this MANCOVA, because students were more likely to be younger and professionals were more likely to be older.

Assumptions for each MANOVA or MANCOVA were checked, including that there were no outliers. Scatterplots were also examined to ensure there were no non-linear relationships between the independent variable and dependent variables in each analysis. Wilk's Lambda was used to judge the significance of multivariate tests. F values were used to assess the significance of univariate tests.

Immediately prior to conducting the primary analyses addressing the research questions, and as a check that participants' ratings of the likelihood of recommending screening did not vary due to the type of cancer described, a Cochran's Q test was used to compare mean scores for the 3 vignettes depicting female patients, for both across patients with Intellectual Disabilities and patients with chronic health conditions. Cochran's Q test is a non-parametric statistic analogous to a one-way repeated measures ANOVA, to determine if there were any differences by type of cancer screening, for both female patients with Intellectual Disabilities and female patients with chronic health conditions, across the three different types of cancer screening. McNemar's tests, a non-parametric test similar to a dependent samples t-test, were used to compare mean ratings for each of the four types of cancer screening, to compare the scores for the patients with Intellectual Disabilities to the patients with chronic health conditions. In addition, McNemar's tests were used to compare the two vignettes regarding colorectal cancer, to determine whether ratings differed significantly due to gender of the patient described. Because the likelihood ratings scores for breast and colorectal cancer screening had a ceiling effect, with most participants choosing "6", scores were dichotomized into "6" and "5 or less". In

addition, because the likelihood ratings scores for cervical cancer screening were bimodal, centred around “1” and “6”, scores were dichotomized into “3 or less” and “4 or more”.

Four forced entry multiple logistic regressions were then used to examine the ability of CLAS-ID subscale scores to predict participants’ ratings of their anticipated likelihood of recommending screening (mammography, Pap test, fecal immunochemical testing for male and female patients) to hypothetical patients with Intellectual Disabilities. Multiple logistic regression develops a model, consisting of several factors, that estimates the probability that an event occurs in the outcomes observed (Polit, 2010). This outcome is always dichotomous (two categories for the outcome). In this case, the CLAS-ID subscale scores were used to predict the participants’ ratings of their anticipated likelihood of recommending a specific type of cancer screening to their patients. Multiple logistic regression was used, rather than multiple linear regression, because once the dependent variables outliers (outliers for the anticipated likelihood of recommending cancer screening scores) were removed, as recommended by Polit (2010), all remaining data points were dichotomous. Polit recommends removing dependent variable outliers for multiple linear regression, because multiple linear regression is very sensitive to outliers. To conduct the analyses, all likelihood scores were dichotomized, with scores of 5 or less in one group and scores of 6 in the second (breast and colorectal cancer screening) or scores of 3 or less in one group and scores of 4 or more in another (cervical cancer screening).

Based on previous research, it was expected that higher scores on the CLAS-ID Similarity and Empowerment subscales would predict increased likelihood of anticipating recommending cancer screening. My rationale was that if participants believe people with Intellectual Disabilities are similar to the general population and should be empowered to take control in their lives, then participants are more likely to recommend screening. Lower scores (indicating

more negative attitudes) on the CLAS-ID Exclusion subscale were expected to predict decreased likelihood of anticipating recommending cancer screening. My rationale was that when participants have more negative attitudes and believe that individuals with Intellectual Disabilities should not be included in society, participants would not recommend screening in a manner similar to the general population. I was uncertain whether the CLAS-ID Sheltering subscale would predict anticipated likelihood of recommending cancer screening, because some research indicates that higher scores on this subscale indicate more negative attitudes (Henry et al., 1996), while other research indicates higher scores on this subscale indicate more positive attitudes (Ouellette-Kuntz, 2012). Thus, no hypothesis regarding the relation of this subscale score to likelihood of recommending screening was formulated.

Because previous research does not provide any information to suggest the relative importance of the subscales for predicting ratings of anticipated likelihood of recommending screening, no planned order of entry of independent variables was developed. Instead, a forced block entry multiple logistic regression was used, because it allowed assessment of the simultaneous contribution of all subscale scores on the dependent variable. Because preliminary analyses indicated demographic variables and experience were related to CLAS-ID subscales, these were controlled for by entering them into an initial separate block. Thus, for all four multiple logistic regressions, the five demographic and experience variables were entered simultaneously in block 1, and the 4 CLAS-ID subscale scores were entered simultaneously in block 2. All block 1 variables were retained in the full models that contained block 2. This was done because: (1) according to Polit (2010) and Tabachnick and Fidell (2011), forced entry is more theoretically parsimonious than using forward or backward stepwise regression, because the latter does not have a theoretical basis for removing variables from the regression; and (2)

preliminary analyses and previous research indicate the block 1 variables were likely to be related to attitude scores. Thus, leaving all demographic variables in the model allowed me to control for the effect of the demographic variables before assessing the effect of the CLAS-ID subscales scores on the dependent variables.

The Hosmer and Lemeshow Test was used for both block 1 models and the full models, to determine if the models were a good fit for the data. A non-significant result of this test indicates that the model accurately predicts the dependent variable. The Nagelkerke R^2 values for the block 1 model and the full model were examined, to determine the contribution of the predictor variables to the variability of the dependent variable. The Nagelkerke R^2 was chosen over the Cox and Snell R^2 , because the former extends the possible range of the R^2 to value of 1, which eases interpretation. The beta coefficients for individual predictor variables in the block 1 model and full model were also examined to determine if any predictors made a significant unique contribution to predicting the dependent variable. Wald Chi-square tests were used to do this. The results of these tests are presented in the following chapter (Chapter 7).

Qualitative Phase Research Methods

The qualitative phase of the current study was conducted following the quantitative phase, mainly due to difficulties with participant recruitment for the qualitative phase. While the phases took place sequentially, they were conducted independently and converge during the interpretation of results, presented in Chapter 9. In the following section, I present the methods specific to the qualitative phase. The findings from the qualitative phase are presented in Chapter 8, following the quantitative findings chapter.

Research questions.

The specific research question for the open-ended interview phase of the study was: What are the experiences of primary care providers in recommending cancer screening to their patients with Intellectual Disabilities? A secondary aim was to explore the other factors related to participants' decision to recommend or not recommend cancer screening to their patients with Intellectual Disabilities. It was expected that these results would help place the survey phase results, which examined a single factor in relation to cancer screening recommendation, into the larger patient care context and would serve to help ground the study in the clinical setting.

Instruments.

Open-ended interview guide.

An initial interview guide was developed for the interview phase of the study before the survey phase was complete. This original interview guide was based primarily on the written vignettes presented in the survey. However, given the unsolicited written comments some participants included in their survey concerning the applicability of the CLAS-ID and the vignettes to the clinical setting, a new interview guide was developed (see Appendix B). This new interview guide focused on exploring how primary care providers recommend cancer screening in general, not solely to their patients with Intellectual Disabilities. Given the changing cancer screening guidelines for all three types of screening, it was thought that enquiring regarding the promotion of cancer screening in general would generate important data that would help place the survey results into the larger care context. The new interview guide also included a question regarding participants' working definition of Intellectual Disabilities and their perspective on their role in providing primary care to individuals with Intellectual Disabilities,

issues that were also identified during the survey analyses. This question was included because, based on some of the unsolicited written comments on the survey, it is possible that participants considered some disabilities, such as cognitive impairment due to stroke, to meet criteria for an Intellectual Disability, although typically these disorders are not considered an Intellectual Disability. The guide also included a question regarding potential factors participants consider before recommending each type of cancer screening, both to their patients in general, and to their patients with Intellectual Disabilities. Finally, the interview guide included a question for participants regarding whether they had the specific experience of recommending each type of cancer screening to a patient with Intellectual Disabilities. The interview concluded with asking participants if they had any further comments to add, either concerning promoting cancer screening or providing care to people with Intellectual Disabilities in general.

Data collection.

Participant recruitment.

Participants for the interview phase of the study were recruited using convenience sampling, similar to the quantitative phase, although the recruitment procedure was conducted differently. In total, 13 family physicians provided information with their completed survey and gave permission to be contacted concerning participating in the interview phase of the study. After multiple attempts that included contacting these physicians via email and regular mail, only two physicians replied. Both consented to be interviewed and took part.

Due to the low rate of response to take part in interviews by family physicians, permission was sought from the UBC Faculty of Medicine Research Access Committee to send an invitation via email to all current UBC family practice residents (a total sample of approximately 154

residents) to invite them to participate in the interview phase of the study. Following this invitation, 11 residents contacted the author concerning participating in the interview phase of the study. Ten residents subsequently gave consent and took part in interviews.

Procedure.

All interviews were conducted via telephone at a time convenient to participants. Phone interviews were conducted, because participants were recruited across the province. The rationale for this decision was to include the perspective of clinicians practicing in rural areas as they may have different experiences recommending cancer screening. The study research assistant, a skilled qualitative interviewer and masters-prepared nurse, conducted all interviews except for one, which was conducted by the study's author due to logistical challenges. The decision to have an experienced health care professional conduct the interviews was because it was anticipated that this would generate richer data than if the study's primary author, who is not a health care professional, had conducted the interviews. Especially given the clinical content of the interview guide, I anticipated that clinicians would feel more comfortable discussing clinical scenarios with a fellow health professional. An interviewer who was a health professional would be better able to understand the clinical context in which participants provide care, specifically recommend cancer screening, to patients with Intellectual Disabilities.

Participants were sent the survey vignettes and interview guide in advance of the interview, in order to prompt participants' responses concerning this topic. It is possible that providing the interview guide in advance biased participants' answers, although it is also possible that providing the questions in advance allowed participants more time to reflect on their experiences providing care to patients with Intellectual Disabilities, especially with regards to cancer screening. Interviews ranged in length from 30 to 40 minutes

The interviews were transcribed verbatim by a professional transcriptionist. Pauses and breaks in conversation (such as saying “Umm...”) were not included, because this was not important for the purposes of analysis for this study. All participants were given an alpha numeric code to preserve their confidentiality. In addition, all potential identifiers were removed, such as other health professional names, hospital or clinic names, and geographic locations, and instead given an alpha numeric code in order to preserve the confidentiality of participants.

Data analysis.

I analyzed the data from the open-ended interviews using the interpretive description approach, as described by Thorne (2008). First, I 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 tentative coding framework in which codes were grouped under four themes. I then applied this framework to two more interviews and then reviewed the quotes for each code. In some instances, I combined codes, if the codes related to the same phenomenon, or placed codes under larger codes, if the code was a subgroup of a larger phenomenon and did not merit an individual code. This also led to 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 minimal, I then used this framework to code the remaining six interviews, including the two interviews with physicians. The physician interviews were coded last in the event they were special cases, because these participants were more experienced than their counterparts who were trainees. By the end of coding the eighth transcript, saturation was reached. The codes and themes are presented in the next chapter.

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 in the current study. A pragmatic perspective is consistent with a mixed methods approach (Cresswell & 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, the pragmatic approach in the interviews allowed a more detailed explanation of the role of primary care providers in recommending cancer screening, from the perspective of primary care providers themselves. This pragmatic approach was important because it was not possible to observe the patient-physician interactions in which screening is recommended. Rather, the primary care providers own experience with multiple patients was explored in interviews.

Representative credibility is analogous to internal validity in quantitative research (Holloway & Wheeler, 2010; Mayan, 2009). According to Mayan, credibility 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: I sought to recruit both male and female physicians from a wide range of geographic areas. Unfortunately, it was not possible to recruit physicians with a range of experience, as all participants in the interview phase were residents or newly practicing physicians, unlike the survey phase participants, in which the majority were experienced physicians. 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. Memos detailing observations were made while I conducted the data analysis, and I also reflected on the reasons

for the decisions I made when analyzing the data. I then created diagrams to demonstrate the relationships between various themes and subthemes, and how they informed my interpretation of the data.

Finally, interpretive authority was maintained by writing detailed memos throughout the data analysis process, in which I noted the analytic steps I took during the analysis, and how these data related to both previous research and my findings from the survey phase. These analytic steps helped ensure that my interpretation of the data, and the conclusions I drew from it, are credible and trustworthy, and accurately represented the participants' experiences (Holloway & Wheeler). The findings from the qualitative phase are presented in Chapter 8.

Ethical Approval

Prior to presenting the findings from each phase in the following chapters, I will first review the ethical approval process for the study. I obtained ethical approval for both phases simultaneously, because they were drawn from the same participant groups and both phases were part of the larger, mixed methods study, thus the ethical approval process is presented in a single section.

Ethical approval was sought from the University of British Columbia (UBC) Behavioural Research Ethics Board (BREB) and the University of Victoria (UVIC) Research Ethics Board. The proper procedures were also followed for conducting research at the University of Northern British Columbia (UNBC): following UBC BREB approval, approval was sought from the UNBC Provost's office (personal communication, Aug. 8, 2014). In addition, ethical approval was also sought from the UBC Faculty of Medicine Research Access Committee, as the UBC Faculty of Medicine has an additional research application required for researchers wishing to

conduct research with Faculty of Medicine students or residents as participants. Permission was also sought from the UBC, UVIC, and UNBC nursing practitioner program coordinators.

Informed consent was sought from all participants prior to completing the survey. Although a signed consent was not required, information regarding consent and the study was presented prior to completing the survey. This included informing potential participants that completing the survey implied consent. Consent forms are presented for the quantitative in Appendix C and for the qualitative phase in Appendix D.

Student participants were also reassured that their supervisors would not know whether they participated, and their supervisors would not know how the student participants responded to the questions in the questionnaire. Anonymity of student responses was maintained, and no contact information for participants was gathered. Professionals were also notified that their responses would be kept confidential, and the self-addressed return envelopes did not have participants' names or addresses printed on them. All physicians were assigned a participant number, and except for this number, no identifying information was printed on the survey. A list of participants' names and identification numbers are stored in a separate file on a password-protected computer, and this information was not used in the analysis. Residents and nurse practitioner students who completed the online survey were also assigned a participant number for this study, although because online survey respondents completed anonymous surveys, no identifying information such as names were collected.

Informed consent was also sought from interview participants. Potential participants emailed the author and received an invitational letter and consent form. If the clinician wished to participate, he or she completed the consent form and emailed the form to the research assistant.

Verbal consent was also obtained at the beginning of the interview. Consent information was kept separate from the participants' transcripts.

All computer files are stored on a password-protected computer, and all paper data and consent forms are stored in a locked cupboard at the UBC School of Nursing. All survey data will be kept for five years following publication and then destroyed. All audio files will be destroyed, and if transcripts are kept past five years, appropriate measures to ensure confidentiality of data will continue. Electronic questionnaires were distributed through the UBC Voivici Enterprise Feedback Management System. The system's servers are located in Canada, and meet the BC privacy legislation requirements.

There were no anticipated direct harms from this study. Demographic data was reported in such a way as to prevent inadvertently identifying participants. There are no direct benefits to participants. An indirect benefit of this study is that the results of this study will be used to help educate other primary care providers on the importance of recommending cancer screening to individuals with Intellectual Disabilities.

A number of post-approval activities were submitted and approved over the course of this study. They included a revision to the recruitment process (sending physicians paper copies of the survey rather than distributing the email link via email), revising the demographic questionnaire and invitational letter to reflect this change, an amendment for approval to post a poster at the UBC School of Nursing to recruit UBC nurse practitioner students, a revised interview guide and interview recruitment process and revised consent process for the interview phase, and finally giving interview participant a token of appreciation (a \$25 Starbucks card) and recruiting family practice residents in addition to physicians. Additional approval was also

sought by the UBC Faculty of Medicine Research Access Committee in order to recruit UBC family practice residents for interviews. Finally, an extension of the ethical approval was sought in the event that more interview participants needed to be recruited or interviewing participants a second time was required, because ethical approval was set to expire before the qualitative data analysis was complete. No additional recruitment of additional interview participants was judged to be necessary after the qualitative data analysis was complete.

Chapter 6 Conclusion

Given the convergent nature of the study design, the findings from the quantitative and qualitative phases are presented separately: the quantitative results are presented in Chapter 7 and the qualitative results are presented in Chapter 8. In the final chapter, Chapter 9, I merge the study phases during the interpretation, and I interpret the key findings from each phase in relation to the other phase. I then draw conclusions and implications from the study as a whole, and suggest avenues for future study.

CHAPTER 7: Quantitative Results

In this chapter, I present the results of the cross-sectional survey phase of the study. The data analysis of the descriptive interviews will be discussed in Chapter 8. The conclusions I draw from both the survey and the interviews, and the implications of these results, and their relationship to previously published research, are discussed in Chapter 9.

Preliminary Analyses

Prior to conducting the primary analyses, descriptive analyses of the demographic, experience, and practice setting questionnaire were conducted, followed by inferential tests to determine if these variables were interrelated. Descriptive analyses of the CLAS-ID data, and inferential tests to determine if demographic variables were related to CLAS-ID subscale scores followed.

Demographic, experience, and practice setting questionnaire.

The demographic section, in addition for asking basic information regarding age, gender, and profession, also asked participants whether they had any Intellectual Disability-specific training or personal or work experience with people with Intellectual Disabilities. The practice setting section was asked only of physicians, and inquired regarding participants' practice characteristics.

Gender, age, and profession.

Overall, 58 participants were female (56.8% of the total sample), and 44 were male (43.1%, see Table 2). While the overall sample was majority female, this is because the student and resident participants were much more likely to be female. All nine nurse practitioner students reported being female. Similarly, the majority of the family practice residents were also

female (75.0%, n=21), while 25.0% (n=7) were male. In contrast, the majority of family physicians were male (male: 56.9%, n=37 versus female: 43.1%, n=28).

Table 2: Participant’s gender and profession (N=102)

	Nurse practitioner students	Family practice residents	Family physicians	Total
N (%)	n=9 (8.8%)	n=28 (27.5%)	n=65 (63.7%)	n=102 (100%)
Number of females (%)	n=9 (100%)	n=21 (75.0%)	n=28 (43.1%)	n=58 (56.8%)

Participants were grouped into six categories based on their reported age: 25 years of age and younger, 26-35 years, 36-45 years, 46-55 years, 56-65 years, and older than 65 years. In total, 1.0% (n=1) of the sample was under the age of 26 years, 41.6% (n=42) were between the age of 26 to 35 years, 14.9% (n=15) between the age of 36 and 45 years, 17.8% (n=18) between the age of 46 and 55 years, 15.8% (n=16) between the age of 56 and 65 years, and 8.9% (n=9) were older than 65 years of age (see Table 3). As expected, nurse practitioner students and family practice residents were generally younger than practicing family physicians, with the majority of participants in these groups under the age of 36. In addition, all participants over the age of 55 years were physicians. It is important to note, the total sample for the age variable consists of 101 participants, because one physician declined to indicate their age, thus the total sample of 102 was reduced to 101.

Table 3: Participants' age, in categories (N=101)

Percentage (number of participants) in each age group				
Age group	Nurse practitioner students (n=9)	Family practice residents (n=28)	Family physicians (n=64)	Total (N=101)
25 years or younger	0.0% (n=0)	3.6% (n=1)	0.0% (n=0)	1.0% (n=1)
26-35 years	66.7% (n=6)	85.7% (n=24)	18.5% (n=12)	41.6% (n=42)
36-45 years	11.1% (n=1)	10.7% (n=3)	16.9% (n=11)	14.9% (n=15)
46-55 years	22.2% (n=2)	0.0% (n=0)	24.6% (n=16)	17.8% (n=18)
56-65 years	0.0% (n=0)	0.0% (n=0)	24.6% (n=16)	15.8% (n=16)
Older than 65 years	0.0% (n=0)	0.0% (n=0)	13.8% (n=9)	8.9% (n=9)

A series of chi-square tests was conducted to determine if gender, age, and professional status of the participants were interrelated. The gender distribution across the three professional groups differed significantly, as determined by a two-way chi-square test of independence ($\chi^2 (2) = 15.62, p < 0.001$). However, caution should be taken when considering the chi-square value; because the group sizes are very different and there were no male nurse practitioner students included in the survey sample (i.e. n for one cell was less than 5). A two-way chi-square test of independence also revealed a relation between age group and professional groups ($\chi^2 (8) = 46.14, p < 0.001$). Again, caution should be taken in considering this result, because 60% of cells had less than the expected count of 5. A final two-way chi-square test of independence was conducted to determine if age and gender of participants were related. This was significant (χ^2

(4) $\chi^2=25.13, p<0.001$), indicating that younger participants were more likely to be female and older participants were more likely to be male.

Given that a statistically significant relationship was found between professional group and age and between professional group and gender, and that age and gender were also significantly related, no further analyses of demographic factors were conducted by profession. However, the unequal professional group sizes may have impacted the results of the chi-square analyses and previous studies have found effects of profession on CLAS-ID scores. Thus, participants' profession was included in the planned logistic regressions regarding the predictive ability of CLAS-ID scores on anticipated likelihood of recommending cancer screening, in addition to inclusion of age and gender as potential predictors.

Additionally, when the preliminary analyses of the main study independent variables (the four CLAS-ID subscale scores) were examined, a total of 7 participants (all physicians) were outliers on one or more CLAS-ID subscales (their score was more than 1.5 interquartile ranges above or below the median). Thus, for the remainder of the analyses presented in this chapter, these 7 participants were removed, thus the total sample (N) consists of 95 participants, including 58 physicians, unless otherwise stated.

Previous experience with individuals with Intellectual Disabilities.

All participants were asked if they had received any training specific to working with people with Intellectual Disabilities, and were asked whether they had previous personal and professional experience with people with Intellectual Disabilities. As can be seen in Table 4, it appears fewer physicians and residents reported receiving Intellectual Disability-specific training than nurse practitioner students. Some of the participants who reported having this type of

training indicated they had either taken disability-specific courses during their professional training, had previous work experience with people with disabilities that included disability-specific training, or had experienced training while they practiced as a different type of health provider prior to their health professional degree.

Table 4: Participants’ reported prior experience with individuals with Intellectual Disabilities (ID) (N =95)

Type of experience	Percentage (number of participants) who responded “yes”			
	Nurse practitioner students (n=9)	Family practice residents (n=28)	Family physicians (n=58)	Total (N=95)
Do you have any training specific to working with people with ID?	44.4% (n=4)	7.1% (n=2)	3.0% (n=2)	8.4% (n=8)
Do you have any previous work experience specific to working with people with ID?	55.6% (n=5)	39.3% (n=11)	19.7% (n=13)	30.5% (n=29)
Do you have any friends or family members with ID?	55.6% (n=5)	39.3% (n=11)	38.1% (n=21)	39.0% (n=37)

Despite few participants reporting having received Intellectual Disabilities-specific training, relatively more participants reported having previous work experience with people with Intellectual Disabilities (Table 4). In total, 55.6% of nurse practitioner students (n=5), 39.3% of family practice residents (n=11), and 19.7% of physicians (n=13) reported having work

experience specific to working with individuals with Intellectual Disabilities. Through open-ended responses, most nurse practitioner students and residents said their prior experience was through volunteer work, or through work prior to entering their professional degree. In contrast, most physicians said they had experience working with individuals with Intellectual Disabilities as part of their medical practice.

Finally, many participants reported having friends or family members with Intellectual Disabilities (Table 4). In total, 55.6% of nurse practitioner students (n=5), 39.3% of family practice residents (n=11), and 38.1% of physicians (n=21) reported having at least one friend or family member with Intellectual Disabilities. When asked to describe the nature of the relationship in their own words, the most commonly described relationships were with cousins (n=10, 9.8%), siblings (n=4, 3.9%), or relatives by marriage (n=4, 3.9%). Respondents also described other relatives (such as aunts or nieces) with Intellectual Disabilities (n = 12, 11.8%), or friends, neighbours, or children of friends (n =6, 5.9%) who have Intellectual Disabilities.

Physician practice characteristics.

Family physicians were asked additional questions concerning their professional practice and their practice specific to individuals with Intellectual Disabilities. Although these were not included in subsequent inferential analyses, because these questions were not posed to the other groups, descriptive statistics are provided to help describe this group within the sample of respondents. First, the 65 physicians were asked to state how many years they had practiced as a physician, using a categorical response. In total, 18.5% (n=12) reported having 0-5 years of experience, 9.2% (n=6) reported 6-10 years, 6.2% (n=4) reported 11-15 years, 9.2% (n=6) reported 16-20 years, and 56.9% (n=37) of participants reported having more than 20 years of experience practicing as a physician.

Physicians were also asked which health authority in BC they were affiliated with. The majority of physicians were from the Greater Vancouver Area, with 56.9% (n=37) stating they were associated with Vancouver Coastal Health, Fraser Health, or Providence Health. Many physicians also stated that they practiced on Vancouver Island: 23.1% (n=15) were associated with the Vancouver Island Health Authority. Relatively few physicians were from Interior Health (15.4%, n=10) or Northern Health (4.6%, n=3) authorities. Thus, it appears that the majority of physicians who responded to the survey were from the Vancouver area, suggesting that most respondents had urban practices, with relatively fewer practicing in more rural areas of BC.

Physicians were also asked to estimate how many patients with Intellectual Disabilities they provide care to over the course of a year, using the following categories: 0-3 patients, 4-8 patients, 9-15 patients, and more than 15 patients within one year. In total, 9.2% of physicians (n=6) reported seeing 0-3 patients with Intellectual Disabilities over the course of a year, 43.1% (n=28) reported seeing 4-8, 20.0% (n=13) reported seeing 9-15 patients, and 26.2% (n=17) reported seeing more than 15 patients with Intellectual Disabilities over the previous year. These results suggest that people with Intellectual Disabilities may not be a professional focus for many physicians responding to the survey, although most do see some patients with Intellectual Disabilities as part of their practice.

Finally, physicians were also asked if they consider that a significant portion of their practice is devoted to individuals with Intellectual Disabilities. This was a highly subjective question, although it was included to determine if any participants focus on providing care to this group. The majority of participants replied that they do not consider a significant portion of their practice to be devoted to patients with Intellectual Disabilities (89.2%, n=58). Only two

participants replied “yes, definitely” to this question (3.1%), and only four participants replied “yes, somewhat.” (6.2%). Importantly, no respondent chose the option “I do not have patients with Intellectual Disabilities as part of my practice.” Thus, while it appears that physicians do not consider people with Intellectual Disabilities to be a focus of their practice, which is in keeping with the number of patients with Intellectual Disabilities they reported seeing in the past year, they do regularly treat some patients with Intellectual Disabilities as part of their practice.

CLAS-ID scores.

Analyses of distributions.

The distributions of all CLAS-ID subscale scores were assessed for normality. First, boxplots were inspected visually for potential outliers, defined as any score more than 1.5 interquartile ranges above or below the median for that item. The inspection revealed a total of nine participants who had one or more CLAS-ID subscale scores that were outliers (approximately 8.8% of all participants who had complete data, i.e. final sample of 95 participants). There were three outliers for the Empowerment subscale, four outliers for the Exclusion subscale, three outliers for the Sheltering subscale, and two outliers for the Similarity subscale. This finding suggests that there were not particular difficulties with any one subscale. All nine participants who were considered to be outliers and were subsequently removed were male, although their age group varied (one was 36-45, three were 46-55, one was 56-65, and two were older than 65 years). Given the preponderance of males in the sample, the gender of those with outliers is not unexpected. The fact that there was not an apparent age bias also suggests no bias in completing the questionnaire due to age or age-related experience.

Second, the subscale distributions of the full data sample, without outliers removed, were subjected to analyses to assess for skewness and kurtosis. The skewness and kurtosis statistics for each subscale, and standard errors for each statistic, are given in Table 5. The skewness and kurtosis statistics for the Empowerment subscale and Sheltering subscale were close to 0. Because these values range from -1 to 1, it can be assumed that these variables were normally distributed (Pollant, 2013). This was not the case for the other two subscales. The skewness and kurtosis statistics for the Exclusion and Similarity subscales were less than -1 or greater than 1, indicating these data were not normally distributed. Examination of the boxplots revealed that there may be a floor effect for the Exclusion subscale (positive skew) and ceiling effect for the Similarity subscale (negative skew).

Table 5: Skewness and kurtosis statistics (and standard error) for original sample with complete data (N=102) and for the final sample with CLAS-ID outliers removed (N=95)

CLAS-ID subscale	Original sample (N=102)		Final sample with outliers removed (N=95)	
	Skewness (SE)	Kurtosis (SE)	Skewness (SE)	Kurtosis (SE)
Empowerment	-0.609 (0.238)	0.431 (0.472)	-0.171 (0.247)	-0.241 (0.490)
Exclusion	1.202 (0.239)	1.174 (0.472)	0.977 (0.247)	0.159 (0.490)
Sheltering	0.481 (0.238)	-0.136 (0.472)	0.278 (0.247)	-0.210 (0.490)
Similarity	-1.104 (0.238)	1.294 (0.472)	-0.524 (0.247)	-0.392 (0.490)

The skewness and kurtosis statistics were then calculated a second time, with values of the nine outliers identified removed (N=95). As can be seen in the skewness and kurtosis statistics in Table 5, once outliers were removed, all skewness and kurtosis statistics were

between -1 and 1. According to Pollant (2013), this means that the subscales can be considered to have a normal distribution. Thus, subsequent data analyses of the CLAS-ID and vignettes were conducted with the sample of 95 participants.

The mean scores and standard deviations (SDs) for CLAS-ID subscales for the final sample of 95 participants, and for physicians, residents and nurse practitioner student groups, are given in Table 6. Because a higher score on the Empowerment and Similarity subscales indicates more positive attitudes, these two mean scores suggest a relatively positive attitude for the total sample. Similarly, because a lower score on the Exclusion subscale indicates a more positive attitude, the mean for this subscale also suggests a positive attitude. In contrast, the mean for the Exclusion subscale fell near the midpoint of the response scale and therefore does not indicate a trend towards either positive or negative attitudes. As can be seen in Table 6, the pattern of scores for all three groups appears to follow a similar pattern, suggesting there were not major differences in response patterns in the different groups.

Table 6: Descriptive statistics for the CLAS-ID subscales, for total sample and by profession (N=95)

CLAS-ID subscale	Total sample (N=95)		Physicians (n=58)		Family practice residents (n=28)		Nurse practitioner students (n=9)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Empowerment	4.25	0.60	4.09	0.58	4.44	0.53	4.71	0.56
Exclusion	1.56	0.52	1.67	0.57	1.44	0.41	1.30	0.30
Sheltering	2.98	0.73	3.15	0.66	2.71	0.50	2.66	0.62

Analyses of effects of demographic factors on CLAS-ID subscale scores.

Effects of gender of respondents on CLAS-ID subscale scores.

A MANOVA was conducted to determine if CLAS-ID subscale scores differed by gender of the participant. The assumptions for MANOVA were met. The overall Wilk's Lambda was non-significant ($F(4, 90)=2.18, p=0.09$). When the F-values for the individual subscales were examined, only the CLAS-ID Empowerment subscale differed by gender ($F(1, 94)=8.70, p<.01$), with female participants having significantly higher scores on this subscale. This indicates female participants were more likely to hold the attitude that individuals with Intellectual Disabilities should be empowered to take control of their lives. F-values for all other CLAS-ID subscales were non-significant, indicating these subscale scores did not differ significantly due to gender of the participant (Table 7).

Table 7: Multivariate Analysis of Variance of CLAS-ID subscale scores by gender (N=95)

CLAS-ID subscale	Males (n=37)		Females (n=58)		F statistic	p-value
	Mean	SD	Mean	SD	Degrees of freedom=1, 94	
Empowerment	4.03	0.62	4.39	0.55	8.70	<.01
Exclusion	1.67	0.57	1.49	0.48	2.79	.10
Sheltering	3.10	0.64	2.90	0.64	2.11	.15
Similarity	4.94	0.41	5.09	0.40	3.48	.07

Wilk's Lamda $F(4, 90)=2.181, p=0.09$

Effects of age on CLAS-ID subscale scores.

A MANOVA was then conducted next to determine whether CLAS-ID subscale scores differed significantly due to age category of the participants. Because the overall MANOVA examining the effect of gender on CLAS-ID subscale scores was non-significant, gender was not included as a covariate in this analysis. Data from one participant who did not provide an age was excluded. The assumptions for MANOVA were met. The overall Wilk's Lambda was significant ($F(94, 16)=3.86, p<.001$). In addition, the CLAS-ID Empowerment subscale scores ($F(4, 93)=10.50, p>.001$), CLAS-ID Similarity subscale scores ($F(4, 93)=3.17, p=.02$), and CLAS-ID Sheltering subscale scores ($F(4, 93)=6.03, p<.001$) differed significantly by age. These results indicate that younger participants were more likely to believe that individuals with Intellectual Disabilities should be empowered, and that individuals with Intellectual Disabilities are similar to themselves. Younger participants were also less likely to believe that individuals with Intellectual Disabilities are vulnerable and should be protected. There was no significant relationship between age and CLAS-ID Exclusion subscale scores (see Table 8).

Table 8: Multivariate Analysis of Co-Variance of CLAS-ID subscale scores by age group

(N=94)

CLAS-ID subscale	25 years or less and 26-35 years (n=43)		36-45 years (n=14)		46-55 years (n=15)		56-65 years (n=15)		Older than 65 years (n=7)		F statistic	p-value
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
Empowerment	4.58	0.48	3.97	0.54	4.18	0.53	4.10	0.57	3.38	0.44	10.50	<.001
Exclusion	1.41	0.36	1.82	0.69	1.71	0.56	1.58	0.51	1.66	.73	2.20	.08
Sheltering	2.68	0.56	3.08	0.73	3.08	0.47	3.48	0.49	3.05	0.62	6.03	<.001
Similarity	5.16	0.32	4.83	0.41	4.91	0.45	5.04	0.45	4.80	0.43	3.17	.02

Wilk's Lamda: $F(4, 16)=3.86, p<.001$

Effects of professional status on CLAS-ID subscale scores.

A MANCOVA was then conducted to explore the impact of career stage on mean subscale scores of the CLAS-ID. Nurse practitioner student scores were combined with family practice resident scores for this analysis to form a group of trainees (n = 37), whose scores were compared to the group of physicians (n = 58). The assumptions for MANCOVA were met. Age was included as a covariate, because the previously discussed MANOVA revealed that age was related to CLAS-ID subscale scores. The Wilk's Lambda for the age covariate was significant ($F(4, 88)=4.95, p=.001$). In contrast, the Wilk's Lambda for professional status ($F(4, 88)=.93, p=0.45$) and all univariate tests were nonsignificant. This indicates that trainees' scores did not differ significantly from physicians', when controlling for the significant effect of age on CLAS-ID subscale scores (see Table 9).

Table 9: Multivariate Analysis of Variance results of CLAS-ID subscale scores by career stage (N=95).

Outcome variables (CLAS-ID subscales)	Students and residents (Trainees) (n=37) Mean (SD)	Physicians (n=58) Mean (SD)	Between-subjects comparisons	
			F (1,93)	p
Empowerment	4.15 (0.55)	4.09 (0.58)	0.59	0.45
Exclusion	1.41 (0.39)	1.66 (0.57)	3.22	0.08
Sheltering	2.70 (0.52)	3.15 (0.66)	1.70	0.20
Similarity	5.14 (0.36)	4.97 (0.42)	1.10	0.30

Wilk's Lambda for covariate (age): $F(4, 88)=4.95, p=0.001$

Wilk's Lambda for independent variable (career stage): $F(4, 88)=0.96, p=0.45$

Analyses of effects of experience with individuals with Intellectual Disabilities on CLAS-ID subscale scores.

Because few participants reported training experience regarding individuals with Intellectual Disabilities, this was not examined further in relation to CLAS-ID scores. However, two MANOVAs were conducted to test the effect of having personal experience with people with Intellectual Disabilities (having a friend or family member with Intellectual Disabilities) and having work experience specific to people with Intellectual Disabilities on CLAS-ID subscale scores.

First, a MANOVA was conducted to examine the effect of personal experience with individuals with Intellectual Disabilities on CLAS-ID subscale scores. The data of one participant who did not answer the personal experience question was excluded from this analysis.

The assumptions for MANOVA were met. The overall Wilk’s Lambda was non-significant ($F(4, 89)=0.39, p=0.81$), as were all univariate tests (see Table 10). This finding indicates that CLAS-ID subscale scores did not differ due to participants having personal experience with at least one person with an Intellectual Disability.

Table 10: MANOVA to compare CLAS-ID subscale mean scores of participants by reported previous personal experience with individuals with Intellectual Disabilities (N=94)

CLAS-ID Subscale	Do you have a friend or family member with ID?				Tests of Between-subjects effects	
	Yes (n=34)		No (n=60)		Degrees of freedom=1, 93	
	Mean	SD	Mean	SD	F-value	p-value
Empowerment	4.24	.63	4.26	.59	0.01	.93
Exclusion	1.51	.46	1.60	.56	0.63	.43
Sheltering	3.02	.56	2.94	.70	0.32	.57
Similarity	5.06	.41	5.02	.41	0.20	.66

Overall Wilk’s Lambda: $F(4, 89)=0.39, p=.45$

A second MANOVA was conducted to examine the effect of having work experience specific to people with Intellectual Disabilities on CLAS-ID subscale scores. Data from one participant who did not answer the work experience question was excluded. The assumptions for MANOVA were met. The overall Wilk’s Lambda ($F(4, 89)=0.47, p=0.76$) and all univariate tests were non-significant (see Table 11). This indicates that CLAS-ID subscale scores did not differ due to whether participants had previous work experience with people with Intellectual Disabilities.

Table 11: MANOVA to compare CLAS-ID subscale scores of participants by reported previous work experience specific to working with individuals with Intellectual Disabilities (N=94)

CLAS-ID Subscale	Do you have work experience specific to working with people with Intellectual Disabilities?				Tests of Between-subjects effects	
	Yes (n=28)		No (n=66)		Degrees of freedom=1, 93	
	Mean	SD	Mean	SD	F-statistic	p-value
Empowerment	4.32	.68	4.22	.54	0.53	.47
Exclusion	1.46	.48	1.61	.54	1.61	.21
Sheltering	2.87	.66	3.01	.65	0.71	.40
Similarity	5.08	.38	5.02	.42	0.39	.53

Wilk's Lambda: $F(4, 89)=0.47, p=0.76$

Thus, CLAS-ID subscale scores varied significantly due to the age of the participant, and differences were found due to gender for certain subscales. In contrast, CLAS-ID scores did not vary by career stage, once age was accounted for. In addition, having previous work or personal experience with people with Intellectual Disabilities did not affect CLAS-ID scores.

Primary Analyses: Predicting Anticipated Likelihood of Recommending Cancer Screening

The primary analyses for the survey phase used CLAS-ID subscale scores and demographic characteristics (gender and age of participant, professional status, and previous personal and work experience with people with Intellectual Disabilities) to predict participants' anticipated likelihood rating scores for recommending cancer screening to hypothetical patients with Intellectual Disabilities presented in vignettes. Descriptive results for the cancer screening vignette rating scales are described first, followed by a series of inferential tests that were

conducted to determine if participants' rating scores for hypothetical patients differed significantly due to 1) the type of cancer described in the vignette, 2) the gender of the patient described in the vignette, or 3) whether the vignette depicted a patient with an Intellectual Disability or a chronic health condition. These analyses were conducted to help explore whether participants' ratings differed due to these factors prior to conducting analyses aimed at predicting their ratings based on their attitudes towards individuals with Intellectual Disabilities, as measured by the CLAS-ID. Finally, four multiple logistic regressions were conducted to determine if CLAS-ID scores predicted participants' anticipated likelihood of recommending cancer screening to the patients with Intellectual Disabilities presented in vignettes after controlling for demographic and experience factors.

Vignette scale descriptive analysis.

The means and SDs for each cancer vignette were calculated for the 95 participants. There were eight vignettes in total: each asked participants to anticipate the likelihood that they would recommend screening to a hypothetical patient. Participants were asked to indicate their answer on a six-point likelihood scale, with 1 being "Very unlikely" to recommend screening and 6 being "Very likely" to recommend screening. The means and standard deviations for the anticipated likelihood of recommending cancer screening scores for each vignette are presented in Table 12.

Table 12: Descriptive Analyses of Participants' Ratings of their Anticipated Likelihood of Recommending Cancer Screening on a 1 to 6 Scale based on Patient Vignettes (N=95)

Cancer Screening Vignettes	Entire Sample (N=95)		Physicians (n=58)		Family practice residents (n=28)		Nurse practitioner students (n=9)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Breast-ID	5.74	0.98	5.71	1.06	5.74	0.97	6.00	0.00
Breast - CH	5.79	0.85	5.78	0.86	5.75	0.97	6.00	0.00
Cervical-ID	4.69	1.94	4.71	1.96	4.14	2.07	5.78	0.44
Cervical-CH	4.43	1.90	4.43	1.91	4.00	2.00	5.78	0.44
Female colorectal-ID	5.78	0.90	5.74	0.95	5.79	0.96	6.00	0.00
Female colorectal-CH	5.78	0.90	5.74	0.95	5.79	0.96	6.00	0.00
Male colorectal-ID	5.78	0.90	5.74	0.95	5.79	0.96	6.00	0.00
Male colorectal-CH	5.78	0.90	5.74	0.95	5.79	0.96	6.00	0.00

*ID=Intellectual Disabilities, CH=chronic health condition

A possible explanation for this may be the open-ended written comments supplied by several physicians. They wrote that they would not recommend cervical cancer screening to their patients because the patients were under the age of 21 (one of the patients in the vignettes was 20

and one of the patients presented in the vignettes was 19) and the Canadian Task Force on Preventive Health Care recommends against cervical cancer in women under the age of 21. However, at the time of the development of the survey, the BC Cancer Agency recommended cervical cancer screening commence at the age of 21 or within three years of initiating sexual activity, whichever came first. Several physicians wrote that they would not recommend screening due to the CTFHPC guidelines. In addition, one physician noted on their survey that one of the cervical cancer screening patients would have a different screening protocol because she was immunocompromised (the patient in the vignette had a kidney transplant as a young child). Thus, it is likely that the lower mean scores for this item, and greater variance, were due to the age of the patients in the vignettes and not participants' attitudes towards the benefit of cervical cancer screening, and also based on the means it appears that participants' were not less likely to recommend cancer screening to individuals with Intellectual Disabilities.

Comparison of ratings of likelihood of recommending cancer screening.

McNemar's tests were conducted to determine if participants were equally likely to choose "6", indicating a relatively stronger likelihood of recommending breast cancer screening, to patients with Intellectual Disabilities and chronic health conditions. The results were non-significant ($p=1.00$). Within the sample, 89.5% chose "6" for the participant with Intellectual Disabilities and 90.5% chose "6" for the participant with a chronic health condition (see Table 13).

Table 13: Likelihood of recommending cancer screening: patients with Intellectual Disabilities and patients with chronic health conditions (N=95)

Vignette	Highly likely to recommend screening to patient with ID (%)	Highly likely to recommend screening to patient with chronic health condition (%)
Breast	n=85 (89.5%)	n=86 (90.5%)
Cervical	n=70 (73.7%)	n=69 (72.6%)
Female colorectal	n=86 (90.5%)	n=86 (90.5%)
Male colorectal	n=86 (90.5%)	n=86 (90.5%)

* The cut-off for breast and colorectal cancer screening was 6, for cervical cancer screening the cut-off was 4 or above.

An additional McNemar's test was then conducted on ratings regarding cervical cancer screening. Once again, there were no difference by whether the patient had an Intellectual Disability or a chronic health condition, according to the McNemar's test ($p=1.00$). Of the sample, 73.7% were relatively more likely (rating of 4 or greater) to recommend cervical cancer screening to the patient with Intellectual Disabilities, and 72.6% were relatively more likely to recommend cervical cancer screening to the patient with a chronic health condition (see Table 13).

The next two tests compared ratings of likelihood of recommending colorectal screening. For female patients, there was no difference in rating scores when comparing the patient with Intellectual Disabilities to the patient with a chronic health condition: The McNemar's test was non-significant ($p=1.00$). In total, 90.5% of participants were relatively more likely to recommend colorectal cancer screening for the female patient with Intellectual Disabilities and 90.5% for the female patient with a chronic health condition (see Table 13). A similar result was

found for the male patients in need of colorectal cancer screening; the McNemar's test was non-significant ($p=1.00$). Of the participants, 90.5% were relatively more likely to recommend colorectal cancer screening to the male patient with Intellectual Disabilities and 90.5% to the male patient with a chronic health condition.

In addition, a McNemar's test was conducted to compare the female patient with Intellectual Disabilities in need of colorectal cancer screening to the male patient with an Intellectual Disability in need of colorectal cancer screening, and an additional test was conducted to compare the female patient with a chronic health condition to the male patient with a chronic health condition, who were both in need of colorectal cancer screening. There were no differences between female patients with Intellectual Disabilities and male patients with Intellectual Disabilities who were in need of colorectal cancer screening ($p=1.00$), with 90.5% of participants rating a "6" for the female patient with an Intellectual Disability and 90.5% of participants rating a "6" for the male patient with an Intellectual Disability. Similar results were found when the female patient with a chronic health condition in need of colorectal cancer screening was compared to the male patient with a chronic health condition in need of colorectal cancer screening.

These results indicate that there was no difference in likelihood of recommending screening due to whether the hypothetical patient had an Intellectual Disability or a chronic health condition. This is important because it means that, if a participant was unlikely to recommend a form of screening to a patient with Intellectual Disabilities, it not due to the fact that the patient had an Intellectual Disability rather than a chronic health condition. In addition, it appears that gender of the participant did not influence whether the participant would

recommend colorectal cancer screening, regardless of whether the patient had an Intellectual Disability or chronic health condition.

A Cochran’s *Q* test was conducted to compare the female patients with Intellectual Disabilities for breast, cervical, and colorectal cancer screening vignette ratings, dichotomized into low and high scoring ratings. The Cochran’s *Q* test was significant ($N=95$, $Q(2)=15.55$, $p<0.001$), indicating there were differences by type of screening among the female patients with Intellectual Disabilities (see Table 14). While 89.5% of the sample rated a high score for breast cancer screening and 90.5% of the sample rated a high score for the colorectal cancer screening for the female patient, only 73.7% of the sample rated a high score for the cervical cancer screening vignette.

Table 14: Likelihood of recommending different types of screening (N=95)

	Highly likely to recommend breast cancer screening	Highly likely to recommend cervical cancer screening	Highly likely to recommend colorectal cancer screening to the female patient
Patient with ID	n=85 (89.5%)	n=70 (73.7%)	n=86 (90.5%)
Patient with chronic health condition	n=86 (90.5%)	n=69 (72.6%)	n=86 (90.5%)

*Cut-off for breast and colorectal cancer screening was 6; for cervical cancer screening, the cut-off was 4 and above.

A similar result was found when a Cochran’s *Q* test was conducted to compare the female patients with a chronic health condition for breast, cervical, and colorectal cancer screening vignette ratings, dichotomized into low and high scoring ratings. The second Cochran’s *Q* test was significant ($N=95$, $Q(2)=18.06$, $p<.001$), indicating that among the female

patients with chronic health conditions, there were differences by cancer screening type (see Table 14). While 90.5% of the sample rated a high score for breast cancer screening and 90.5% of the sample rated a high score for colorectal cancer screening for a female patient with a chronic health condition, only 72.6% of the sample rated a high score for the cervical cancer screening vignette with a patient with a chronic health condition. This result, taken together with the results discussed earlier, indicate that participants were less likely to highly recommend cervical cancer screening relative to breast and colorectal cancer screening, regardless of whether the patient had an Intellectual Disability or chronic health condition.

Multiple logistic regression analyses.

The final set of analyses included four multiple logistic regressions, one for each vignette depicting a patient with an Intellectual Disability. These were used to determine whether CLAS-ID scores, when controlling for participant demographic characteristics, would predict whether participants were more likely to recommend cancer screening for an individual with an Intellectual Disability. The predictor variables for all four regressions were the same. I used forced entry for all of the variables, because I had no theoretical basis for order of entry. It has been recommended that forced entry or theoretical entry is preferred over stepwise addition or stepwise subtraction, because the latter two methods are post-hoc and are based on the data, not a theoretical underpinning (Polit, 2010; Tabachnick & Fidell 2013).

I entered the predictor variables in two blocks. The first block contained predictors that either were related to CLAS-ID subscale scores in my preliminary analyses, or predictors that previous research has shown are related to CLAS-ID subscale scores. The predictor variables in block one included gender of the participant (dichotomous), age of the participant (categorical), having a friend or family member with an Intellectual Disability (dichotomous), having previous

work experience with people with Intellectual Disabilities (dichotomous), and career stage (dichotomous; NP student or resident (trainee) versus family physician). The four predictor variables entered into block two were the four CLAS-ID subscale scores: Empowerment, Exclusion, Sheltering, and Similarity. The results of these four multiple logistic regression analyses are described separately below.

In total, 95 participants were included in these analyses. According to Polit (2010), generally a researcher should have 10-20 participants per each predictor variable entered into a multiple regression. Because the present study included 95 participants and 9 predictors, it is likely that there was sufficient power to detect a large effect of the predictor variables on the dependent variables in the multiple logistic regressions.

Breast cancer screening recommendation in a patient with Intellectual Disabilities.

A forced entry multiple logistic regression analysis was conducted to determine if the five demographic predictor variables described above (age and gender of participant, personal and professional experience with people with Intellectual Disabilities, and professional status) entered into block 1, and the four CLAS-ID subscales (Empowerment, Exclusion, Sheltering, and Similarity) entered into block 2, predicted the anticipated likelihood of recommending breast cancer screening to the hypothetical patient with Intellectual Disabilities presented in the vignette. The tests for Block 1 (demographic predictors only) and tests for the full model (demographic predictors and CLAS-ID subscales) were considered separately, in order to determine if adding CLAS-ID subscales to demographic information contributed to predicting ratings indicating participants were relatively more likely to recommend breast cancer screening.

For Block 1, the Hosmer and Lemeshow Test was non-significant ($\chi^2(8) = 1.992$, $p=0.981$), indicating that the block 1 predictors were a good fit for the data. The R^2 value for Block 1 was 0.204, indicating that the five predictors in Block 1 predicted 20% of the variance in the data. When the beta-coefficients for the Block 1 predictors were examined, only the coefficient for gender of the participant approached significance ($\beta=1.378$, $SE=0.771$, $Wald=3.196$, $p=0.074$), indicating female participants were more likely to recommend breast cancer screening (see Table 15).

Table 15: Results of a Multiple Logistic Regression Analysis to Predict Participants' Ratings of their Anticipated Likelihood of Recommending Breast Cancer Screening for a Female Patient with an Intellectual Disability presented in a Vignette (N=95)

	Beta-coefficient	SE	Wald	P-value
Model 1				
Experience (physician)	-.150	.944	.025	.874
Gender (female)	1.378	.771	3.196	.074
Age (36-45)	.052	1.002	.003	.958
Age (46-55)	19.588	10024.136	.000	.998
Age (56-65)	-.089	1.074	.007	.934
Age (older than 65)	20.199	15164.638	.000	.999
FamID (no)	.232	.770	.090	.764
WorkID (no)	.338	.869	.151	.697
Constant	.740	.981	.568	.451
Model 2				
Experience (physician)	-.091	1.058	.007	.932
Gender (female)	1.694	.986	2.952	.086
Age (36-45)	1.887	1.552	1.480	.224
Age (46-55)	21.222	9043.481	.000	.998
Age (56-65)	.755	1.393	.294	.558
Age (older than 65)	20.865	12592.494	.000	.999
FamID (no)	1.222	.949	1.600	.198
WorkID (no)	-.199	1.060	.035	.851
CLAS-ID Empowerment	-1.680	1.243	1.827	.176
CLAS-ID Exclusion	-2.617	1.178	4.934	.026
CLAS-ID Sheltering	-.230	.896	.066	.797
CLAS-ID Similarity	1.796	1.811	.983	.321
Constant	3.289	9.107	.130	.718

*non-reference category in parentheses for dichotomous variables

Model 1: Hosmer and Lemeshow test: $\chi^2(8)=1.992$, $p=0.981$, Nagelkerke $R^2=0.204$

Model 2: Hosmer and Lemeshow test: $\chi^2(8)=18.339$, $p=0.019$, Nagelkerke $R^2=0.39$

The overall statistics for the full model were examined next. The Hosmer and Lemeshow Test was significant ($\chi^2(8)=18.339, p=0.019$) indicating that the full model was not a good fit for the model. Nonetheless, adding the four CLAS-ID variables increased the Nagelkerke R^2 to 0.396, indicating that the predictors in the full model explained approximately 40% of the variance in scores reflecting likelihood of recommending breast cancer screening for a patient with an Intellectual Disability.

When the beta coefficients for the predictors of the full model were examined, gender of the participant continued to display a trend towards significance ($\beta =1.694, SE=0.986, Wald=2.952, p=0.086$). Importantly, the CLAS-ID Exclusion subscale beta-coefficient was significant ($\beta =-2.617, SE=1.178, Wald=4.934, p=0.026$). This indicates that participants who held a stronger belief that individuals with Intellectual Disabilities should be kept segregated from society were less likely to anticipate recommending breast cancer screening to the patient with Intellectual Disability presented in the vignette.

Cervical cancer screening recommendation in a patient with Intellectual Disabilities.

A second forced entry multiple logistic regression analysis was conducted to determine if the five demographic predictor variables and four CLAS-ID subscales predicted a greater anticipated likelihood of recommending cervical cancer screening to the patient in the vignette. The Hosmer and Lemeshow Test for the block 1 variables was non-significant ($\chi^2(8) = 3.066, p=0.930$), indicating the group of predictors were a good fit for the data. The Nagelkerke R^2 was 0.093, indicating the five predictors in Block 1 predicted approximately 9% of the variance in cervical cancer screening vignette scores. When the beta-coefficients for the Block 1 predictors were examined, none were significant; no individual predictor significantly contributed to predicting scores.

For the full model, the Hosmer and Lemeshow Test was non-significant ($\chi^2 (8)=4.490$, $p=0.810$), indicating the full model is accurate at predicting the observed dependent variable values. Adding the four CLAS-ID variables increased the amount of variance explained by the predictors; the Nagelkerke R^2 grew to 0.123. This indicates the full model explained 12% of the variance in cervical cancer screening recommendation scores. No Block 2 predictor variables were significant (see Table 16). This indicates that none of the predictors in the model significantly contributed to predicting whether participants were relatively more likely to recommend cervical cancer screening to a hypothetical patient with an Intellectual Disability.

Table 16: Results of a Multiple Logistic Regression Analysis to Predict Participants' Ratings of their Anticipated Likelihood of Recommending Cervical Cancer Screening for a Female Patient with an Intellectual Disability presented in a Vignette (N=95)

	Beta-coefficient	SE	Wald	P-value
Model 1				
Experience (physician)	.026	.671	.001	.969
Gender (female)	.509	.571	.794	.373
Age (36-45)	1.249	.888	1.978	.160
Age (46-55)	1.333	.938	2.021	.155
Age (56-65)	.559	.855	.428	.513
Age (older than 65)	.721	1.093	.435	.509
FamID (no)	-.280	.557	.253	.615
WorkID (no)	-.411	.587	.491	.484
Constant	.694	.785	.781	.377
Model 2				
Experience (physician)	-.017	.692	.001	.980
Gender (female)	.557	.581	.918	.338
Age (36-45)	1.197	.949	1.592	.207
Age (46-55)	1.275	.975	1.710	.191
Age (56-65)	.553	.941	.345	.557
Age (older than 65)	.754	1.238	.370	.543
FamID (no)	-.325	.571	.324	.569
WorkID (no)	-.391	.592	.436	.509
CLAS-ID Empowerment	.290	.588	.244	.622
CLAS-ID Exclusion	-.441	.648	.462	.497
CLAS-ID Sheltering	.213	.493	.188	.665
CLAS-ID Similarity	-1.138	.930	1.497	.221
Constant	5.304	5.489	.934	.334

*non-reference category in parentheses for dichotomous variables

Model 1: Hosmer and Lemeshow test: $\chi^2(8)=3.066, p=0.930$, Nagelkerke $R^2=0.093$

Model 2: Hosmer and Lemeshow test: $\chi^2(8)=4.490, p=0.810$, Nagelkerke $R^2=0.133$

Colorectal cancer screening recommendation to a female patient with Intellectual Disabilities.

The third analysis was conducted to determine if demographic variables described and the four CLAS-ID subscales predicted a relatively stronger likelihood of recommending colorectal cancer screening to the hypothetical female patient with an Intellectual Disability presented in the vignette. The Hosmer and Lemeshow Test was non-significant ($\chi^2 (8) = 4.448$, $p=0.815$), indicating that the block 1 predictors were a good fit for the data. The Nagelkerke R^2 was 0.147, indicating that Block 1 predicted 15% of the variance in the relative likelihood of recommending colorectal cancer screening for the female patient in the vignette. When the beta-coefficients for Block 1 were examined, none achieved significance (see Table 17).

Table 17: Results of a Multiple Logistic Regression Analysis to Predict Participants' Ratings of their Anticipated Likelihood of Recommending Colorectal Cancer Screening for a Female Patient with an Intellectual Disability presented in a Vignette (N=95)

	Beta-coefficient	SE	Wald	P-value
Model 1				
Experience (physician)	-1.163	1.148	1.026	.311
Gender (female)	1.338	.850	2.477	.116
Age (36-45)	-.203	1.141	.032	.859
Age (46-55)	1.034	1.441	.514	.473
Age (56-65)	.236	1.227	.037	.848
Age (older than 65)	1.094	1.560	.492	.483
FamID (no)	-.137	.846	.026	.871
WorkID (no)	1.258	.842	2.232	.135
Constant	1.418	1.127	1.583	.208
Model 2				
Experience (physician)	-1.787	1.605	1.240	.265
Gender (female)	1.513	1.049	2.078	.149
Age (36-45)	2.261	2.154	1.101	.294
Age (46-55)	2.176	1.822	1.426	.232
Age (56-65)	1.371	1.836	.557	.455
Age (older than 65)	2.308	2.299	1.007	.316
FamID (no)	.266	.986	.073	.788
WorkID (no)	2.2093	1.127	3.451	.063
CLAS-ID Empowerment	.581	1.085	.286	.593
CLAS-ID Exclusion	-3.314	1.320	6.298	.012
CLAS-ID Sheltering	.113	1.084	.011	.917
CLAS-ID Similarity	-2.122	1.815	1.366	.242
Constant	5.304	10.041	1.911	.167

*non-reference category in parentheses for dichotomous variables

Model 1: Hosmer and Lemeshow test: $\chi^2(8)=4.448, p=0.815, Nagelkerke R^2=0.147$

Model 2: Hosmer and Lemeshow test: $\chi^2(8)=5.025, p=0.755, Nagelkerke R^2=0.356$

For the full model, the Hosmer and Lemeshow Test was also non-significant (χ^2 (8)=5.028, $p=0.755$) indicating that the full model was a good fit for the data. Adding the four CLAS-ID variables increased the amount of variance explained, as seen by the new Nagelkerke R^2 of 0.356. This means that the model explained 36% of the variance in the relative likelihood of recommending colorectal cancer screening for the female patient. The beta coefficient for the CLAS-ID Exclusion subscale was significant ($\beta = -3.314$, $SE=1.320$, $Wald=6.298$, $p=.012$). This indicates that participants with a higher score on the Exclusion subscale, who are more likely to hold the belief that individuals with Intellectual Disabilities should be segregated from society, were less likely to anticipate recommending colorectal cancer screening to the female patient in the vignette. Participants who did not have previous work experience with individuals with Intellectual Disabilities were also somewhat more likely to anticipate recommending colorectal cancer screening to the female patient in the vignette, as evidenced by the marginally significant beta-coefficient for that variable ($\beta = 2.093$, $SE=1.127$, $Wald=3.451$, $p=0.063$).

Colorectal cancer screening recommendation to a male patient with Intellectual Disabilities.

The final multiple logistic regression analysis was conducted to determine if demographic variables and the four CLAS-ID subscales predicted a relatively greater anticipated likelihood of recommending colorectal cancer screening to the hypothetical male patient with an Intellectual Disability presented in the vignette. The Hosmer and Lemeshow Test for Block 1 was non-significant (χ^2 (8) = 4.448, $p=0.815$). Thus, Block 1 was a good fit for the data. The Nagelkerke R^2 of 0.147 indicated the five predictors in Block 1 predicted 15% of the variance in the relative likelihood of recommending colorectal cancer screening for the male patient in the vignette. None of the individual variables in Block 1 achieved a significant beta-coefficient; they

did not have significant individual contributions to predicting the independent variable (Table 18).

Table 18: Results of a Multiple Logistic Regression Analysis to Predict Participants' Ratings of their Anticipated Likelihood of Recommending Colorectal Cancer Screening for a Male Patient with an Intellectual Disability presented in a Vignette (N=95)

	Beta-coefficient	SE	Wald	P-value
Model 1				
Experience (physician)	-1.163	1.148	1.026	.311
Gender (female)	1.338	.850	2.477	.116
Age (36-45)	-.203	1.141	.032	.859
Age (46-55)	1.034	1.441	.514	.473
Age (56-65)	.236	1.227	.037	.848
Age (older than 65)	1.094	1.560	.492	.483
FamID (no)	-.137	.846	.026	.871
WorkID (no)	1.258	.842	2.232	.135
Constant	1.418	1.127	1.583	.208
Model 2				
Experience (physician)	-1.787	1.605	1.240	.265
Gender (female)	1.513	1.049	2.078	.149
Age (36-45)	2.261	2.154	1.101	.294
Age (46-55)	2.176	1.822	1.426	.232
Age (56-65)	1.371	1.836	.557	.455
Age (older than 65)	2.308	2.299	1.007	.316
FamID (no)	.266	.986	.073	.788
WorkID (no)	2.2093	1.127	3.451	.063
CLAS-ID Empowerment	.581	1.085	.286	.593
CLAS-ID Exclusion	-3.314	1.320	6.298	.012
CLAS-ID Sheltering	.113	1.084	.011	.917
CLAS-ID Similarity	-2.122	1.815	1.366	.242
Constant	5.304	10.041	1.911	.167

*non-reference category in parentheses for dichotomous variables

Model 1: Hosmer and Lemeshow test: $\chi^2(8)=4.448, p=0.815, Nagelkerke R^2=0.147$

Model 2: Hosmer and Lemeshow test: $\chi^2(8)=5.025, p=0.755, Nagelkerke R^2=0.356$

The Hosmer and Lemeshow Test was also non-significant for the full model ($\chi^2(8)=5.028, p=0.755$), indicating that it was also a good fit for the data. Adding the four CLAS-ID variables increased the amount of variance in the relative likelihood of recommending screening explained by the predictors, to 36%, as shown by the Nagelkerke R^2 value of 0.356. The beta-coefficient for the CLAS-ID Exclusion subscale was significant ($\beta = -3.314, SE=1.320, Wald=6.298, p=.012$, see Table 18). This indicates that participants with a higher score on the Exclusion subscale, and thus more likely to hold the belief that individuals with Intellectual Disabilities should be segregated from society, were relatively less likely to anticipate recommending colorectal cancer screening to the male patient in the vignette. As with the female patient, participants who did not have previous work experience with individuals with Intellectual Disabilities were somewhat more likely to anticipate recommending colorectal cancer screening to the male patient in the vignette, as shown by the marginally significant beta-coefficient ($\beta = 2.093, SE=1.127, Wald=3.451, p=0.063$).

Chapter 7 Conclusion

The results of the analyses described here revealed several interesting findings. First, preliminary analyses revealed that female participants held a significantly stronger belief than male participants that individuals with Intellectual Disabilities should be empowered to take control of their lives. Younger participants also held stronger beliefs that individuals with Intellectual Disabilities should be empowered, are similar to the participants themselves, and need to be sheltered from society. No differences were found regarding the participants' professional status. Those who were trainees did not hold different beliefs than those who were physicians, once participants' age was controlled for. Similarly, participants' previous personal

and work experience with individuals with Intellectual Disabilities did not significantly affect their attitudes, as measured by the CLAS-ID.

The primary analyses also revealed some interesting results regarding the likelihood that participants would recommend cancer screening. This did not differ significantly, within types of screening, due to whether the patient described in the vignette had an Intellectual Disability or a chronic health condition. The effect of the patient's gender was also not significant for the colorectal cancer screening scenarios, although participants' likelihood of recommending certain types of cancer screening varied significantly, with participants being more likely to recommend breast and colorectal cancer screening relative to cervical cancer screening. However, multiple regression models did indicate that some combinations of factors, as well as some independent factors, significantly predicted how whether participants were more or less likely to recommend specific types of cancer screening for patients with Intellectual Disabilities. For example, participants who held a stronger belief that individuals with Intellectual Disabilities should be kept segregated from society were less likely to anticipate recommending breast cancer screening to the patient with Intellectual Disability presented in the vignette and participants who are more likely to hold the belief that individuals with Intellectual Disabilities should be segregated from society were less likely to anticipate recommending colorectal cancer screening to patients with Intellectual Disabilities, regardless of the gender of the patient in the vignette. Interestingly, no CLAS-ID measured attitudes independently contributed to predicting the relative likelihood or recommending cervical cancer screening. Interestingly, the full model, containing the demographic factors and CLAS-ID scores did not have a good fit for the likelihood data reflecting the relative likelihood of recommending breast cancer screening for the patient with an Intellectual Disability, although it explained 40% of the variation. In contrast, the models for

cervical cancer (12% variability explained) and colorectal cancer screening for female (36% variability explained) and male patients (36% variability explained) | were a good fit. These differing results may, in part, reflect the differences in variability among the data sets. This will be explored further in the Discussion chapter.

It is important to consider that these data explore a single aspect of primary care providers, attitudes towards people with Intellectual Disabilities, in relation to recommending cancer screening to hypothetical patients with Intellectual Disabilities. Many other variables are likely related to whether primary care providers recommend cancer screening to patients with Intellectual Disabilities. In addition, primary care providers' perspectives on their role in promoting cancer screening to all patients in their practice, and their perspectives on their role to provide preventive and primary care to all patients with Intellectual Disabilities, also need to be considered in order to understand their decision-making within the larger care context. In the next chapter, I describe data collected through interviews with family physicians and family practice residents. It was hoped that this would help to better understand the role of primary care providers in recommending cancer screening to patients with Intellectual Disabilities.

CHAPTER 8: Qualitative Results

The previous qualitative research examining receipt of cancer screening in individuals with Intellectual Disabilities seems to suggest that health professionals' attitudes towards people with Intellectual Disabilities influences how these providers go about recommending cancer screening to patients with Intellectual Disabilities. In the survey phase of my dissertation I explored this phenomenon further: I used a standardized attitudes measure to examine if primary care providers' attitudes towards individuals with Intellectual Disabilities in general were related to whether they anticipated recommending cancer screening to hypothetical patients. I did find one component of attitudes, that is, attitudes towards community inclusion, were related to likelihood of recommending cancer screening, with more positive attitudes being related to a higher anticipated likelihood of recommending breast and colorectal cancer screening.

However, according to research reviewed in previous chapters, attitudes are only one possible factor influencing primary care providers' decision to recommend cancer screening. In order to explore any other factors related to cancer screening recommendation that may be at play, and to better understand the context in which cancer screening is recommended, I conducted open-ended interviews with 12 family physicians and family practice residents.

What I learned from participants' interviews is that attitudes are just one factor that contributes to the broader environment in which participants practiced. This environment also consists of features including the geographic location of the participants' practice and the organization of this practice, including, for residents, the role of their preceptor in influencing how they deliver care. These factors all influence to how participants go about providing care, including recommending cancer screening. Importantly, all of these factors are generally similar from patient to patient, and influence how physicians provide care to all patients.

While this medical environment forms the backdrop in which care is delivered, within this environment there is a very important interaction between the patient and the physician. Factors related to this interaction are specific to each individual patient, and these factors may vary greatly from one patient to another. Participants indicated that they experience competing demands when deciding whether to recommend cancer screening to any given patient. On the one hand they weigh the evidence based guidelines and the patient's eligibility according to these guidelines, while on the other hand they consider the benefits and potential harms of screening, and they employ their clinical judgement to make a decision as to whether cancer screening is beneficial to each unique patient. Participants appear to consider multiple factors related to the patient prior to making a decision to recommend or not recommend cancer screening.

In addition to this balance between applying evidence based practice and exercising clinical judgement, some participants also spoke of their desire to grant their patients autonomy in seeking out care, including cancer screening. 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, including cancer screening, that they are eligible for.

In the following chapter, I will first examine two main themes related to the patient-physician interaction: applying evidence based practice and exercising clinical judgement. Next, I will also consider what participants revealed about their desire to grant their patients autonomy within this interaction. Finally, I will then step back and consider the features of the medical environment in which participants practice and how this environment directly and indirectly influences the participants in balancing these competing demands within the medical interaction.

Applying Standards of Practice

A key factor participants consider prior to recommending cancer screening is a patient's eligibility according to evidence-based guidelines and standards of practice. The participants in this study were clearly aware of current national guidelines for cervical cancer screening, and several referenced the ongoing evolution of the Canadian guidelines for breast and colorectal screening in relation to the ever-changing evidence landscape. The national guidelines specify the patient characteristics associated with eligibility for screening, and participants were generally aware of these guidelines. 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 Disabilities, might have additional needs that would need to be taken into consideration either in the recommendation for screening or in the screening process itself. In this aspect of the report on findings, I will begin by describing the manner in which these study participants considered and applied evidence based guidelines in determining whether or not to recommend cancer screening for individual patients, including those with Intellectual Disabilities.

Assessing eligibility for screening.

The participants' accounts suggested that the most common consideration they took into account was the age of the patient. 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, they referenced gender as a key consideration in breast and cervical cancer screening, but none indicated any differential recommendations for male and female patients in relation to colorectal cancer screening.

Risk was another factor mentioned by several of the study participants, particularly in relation to breast and colorectal cancer screening. If the patient had a genetic predisposition or family history of these forms of cancer, participants indicated that they would recommend additional screening in relation to this form of 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 fecal 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.

Within the accounts, there were numerous references to the evolving nature of cancer screening guidelines as the evidence base for screening shifts over time. For example, a few participants described no longer promoting breast self-examination, as a result of changes in the guidelines. An observation I made in relation to this sample of physicians who were primarily residents or recent graduates of medical school was that they seemed particularly attuned to the changing environment related to the evolving nature of the evidence for screening. This seemed to contrast with the reports of the survey respondents who were frequently more experienced physicians. One participant did openly wonder about whether her colleagues who are ten or fifteen years her senior would be as aware of the changing nature of cancer screening guidelines as she is. It is interesting to speculate as to whether more experienced physicians would be as likely to recommend cancer screening according to the new guidelines, and this question will be discussed further in the next chapter.

In summary, participants spoke of considering age and gender of the patient, and also the family history and cancer risk of the patient when deciding whether a patient is eligible for any given form of cancer screening. In addition, they 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. Thus, I have identified that participants make changes to their practice and screening recommendations, based on both the patient's characteristics and eligibility for screening and also as cancer screening guidelines change over time.

Promoting cancer screening to everyone.

When asked how they provide primary care, including promoting cancer screening to their patients with Intellectual Disabilities, participants indicated that they did not consider

Intellectual Disability as a sufficient rationale for withholding a screening recommendation. Further, many emphasized that they would actively promote cancer screening to patients with Intellectual Disabilities in a manner similar to their other patients. For all patients, a key consideration for participants was whether the patient met the eligibility guidelines for screening

When prompted, some participants explicitly stated that they feel it is their role to provide primary care to everyone, regardless of their patients' abilities. 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 Disabilities 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 illustrates the participant's belief that patients with Intellectual Disabilities should receive the same level of care as all other patients, and the belief that patients with Intellectual Disabilities are not a special circumstance and do not require a different form of care.

Some participants acknowledged that patients with Intellectual Disabilities may have additional needs or require additional accommodations during screening. For example, some participants noted that patients with Intellectual Disabilities may be accompanied by caregivers. One participant described the difficulties in needing to coordinate care, in this case cancer screening, with multiple stakeholders, including the patient's caregivers. This coordination may make it more burdensome for participants to provide 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 Disabilities 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 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. However, while they acknowledged that patients with Intellectual Disabilities 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. From their perspective, a patient's needs are considered along with the patient's eligibility for screening prior to participants recommending screening.

Related to the finding that participants do not modify care based solely on a patient's Intellectual Disability, while at the same time recognizing that patients with Intellectual Disabilities may have additional support needs, it is important to reflect on the relatively limited experience that the participants in the interview phase had related to actually providing care to patients with Intellectual Disabilities. The majority of participants were residents, 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 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 Disabilities in a manner similar to other patients, they did recognize that some patients with Intellectual Disabilities 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 Disabilities, should undergo screening, may also reflect their limited experience actually providing care to patients with Intellectual Disabilities.

Exercising Clinical Judgement

Although the participants in this study were well informed about and generally aware of evidence-based guidelines in favour of cancer screening, they also recognized that some patients, including those with Intellectual Disabilities, may have additional needs with respect to screening. In this regard, a key theme that arose in their accounts had to do with tailoring screening recommendations to the individual patient involved. In this process, they described the importance of exercising their clinical judgement.

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 Disabilities, understand the screening process. Participants explained that this assessment of a patient's needs occurs individually for each patient. As one participant described, when asked how one would promote cancer screening to patients with Intellectual Disabilities:

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 resident recognizes that patients with Intellectual Disabilities may have additional needs for screening that may have inherent risks, which may lead the resident to

believe the benefits of screening do not outweigh the risks for each patient, especially for patients with more severe Intellectual Disabilities. Also, while participants spoke of tailoring care for patients with Intellectual Disabilities, some participants were aware of other conditions, such as severe anxiety, that might lead them to tailor the screening recommendation to a patient's needs. This principle that care ought to be tailored to each patient's needs might then result in a situation in which the participant could decide not to recommend screening to a specific patient, because of a judgement that screening may not be in the patient's best interests.

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. On the other hand, these study participants were also aware of possible risks associated with screening. These included such possible conditions as patients' anxiety in relation to the screening process and concerns about patients' ability to cope with follow-up procedures and treatment if their screening test was positive. 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 Disabilities. In contrast, other participants thought that, if their patients were particularly anxious about the possibility of having cancer, and a negative test result would reassure them, leading participants toward recommending screening to 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 more likely to recommend against screening for patients with Intellectual Disabilities, believing the risks might not outweigh the benefits for this group of patients. However, they 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 Disabilities. 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. Participants recognized each patient's unique needs in regards to cancer screening. Thus, while a specific patient may be eligible for screening according to standardized guidelines, a clinician may decide that screening is not in that patient's best interests and consequently not recommend screening.

Granting Patients Autonomy to Choose their Care

Participants in the study frequently described the challenge in that they wished to give patients autonomy to direct their own care, but at the same time wanted to ensure that patients receive the cancer screening that they are eligible for. One example of a patient choosing their own care was portrayed by a resident who described referring an average-risk, asymptomatic patient for a colonoscopy rather than a FIT test. While the resident indicated that they would explain to the patient that this was a more stringent test and not part of usual care, the residents would still refer the patient for the colonoscopy, based on the patient's choice. Other participants indicated that if a woman in her forties, who would generally not be eligible for screening mammography, asked for a mammogram, these clinicians would still refer the patient for the test. 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.

One issue that was discussed during interviews is that patients do not receive the cancer screening they are eligible for due to myriad reasons. One method used to help ensure patients are up to date with screening is when a patient arrives for an appointment for a medical concern, the physician can review the patient's chart and ensure that the patient is up to date with breast, cervical, and colorectal cancer screening. 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.

However, there are also circumstances in which a clinician may not have the opportunity to encourage patients to participate in all cancer screenings. Many participants spoke of realizing during an appointment that a female patient is due for a Pap smear, but lacking the time to perform the test during that appointment. In such instances, the physician asks the patient to book a follow-up appointment for the test. The participant then relies on the female patient to be proactive and return for the test. Similarly, for older women, if a woman is no longer attending appointments for regular Pap smears, then the clinician may not recognize when this patient is due for a mammogram, and may miss the opportunity to promote this form of 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. One clinician described that it may be more difficult to negotiate providing care, including cancer screening, to patients with Intellectual Disabilities who have multiple caregivers involved in their care. Another resident 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 frequently mentioned a strategy that would facilitate promoting screening; if as part of routine care, there was a reminder in patients' charts when they are due for cancer screening, this would help clinicians by reminding them to discuss cancer screening during an appointment.

Situating the Patient-Physician Interaction within the Medical Environment

While the previous discussion has mainly been concerned with the patient-physician interaction, it was apparent from the accounts of these study participants 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 residents, the role of their preceptor in how residents deliver care. Unlike previous themes discussed thus far, the medical environment is not individualized to each patient, rather the influence of the medical environment is similar across patients.

The first consideration is the geographic location of participants' practice, because participants from across BC took part in the study. Approximately half of the participants practiced in an urban or suburban setting and half practiced in a rural setting. Interestingly, when prompted, most study 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 stated that obtaining follow-up procedures following a positive screening result was an issue for their patients, regardless of the geographic location of their practice. This accessibility of care included when a

patient needed a colposcopy performed by a gynecologist or a colonoscopy performed by a surgeon or gastroenterologist.

The participants' clinical experience, both in general and specific to caring for patients with Intellectual Disabilities, also affected their responses. Many participants were residents, and described obtaining advice regarding clinical matters from the preceptor. Participants also frequently indicated that they follow the procedures and care guidelines adhered to by their preceptors. 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 Disabilities as part of routine practice. In addition, unlike the themes related to the individual clinical interaction, the contributors to the medical environment are more consistent across patients.

Chapter 8 Conclusion

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 the qualitative phase of this study clearly held the belief that everyone eligible for screening should obtain screening. Conversely, they were also aware that individuals with Intellectual Disabilities may have additional needs in regards to screening, and these needs may make screening less feasible for some patients. Further, they 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.

CHAPTER 9: Discussion and Conclusions

This mixed methods study had the aim of better understanding how primary care providers recommend cancer screening to patients with Intellectual Disabilities. The quantitative phase revealed that certain types of clinicians' negative attitudes toward community inclusion of people with Intellectual Disabilities predicted their anticipated likelihood of recommending cancer screening to patients with Intellectual Disabilities portrayed in written vignettes. However, results from the qualitative phase of this study indicated that primary care providers' attitudes may have led to them anticipating they would recommend cancer screening to all patients. A key finding from the present study was that primary care providers experience multiple demands when deciding whether to recommend cancer screening to any given patient; they weigh the eligibility of the patient for cancer screening with their clinical judgement in order to determine the best course of care for each patient. This balancing does not occur in a vacuum; rather it is situated within the larger medical environment. This environment comprises the physical structures of their practice, including the geographic location of clinicians' practice and, for residents, the role of their preceptor in supporting their care provision. As reviewed in the previous chapter, the process in which physicians balance competing demands and make a clinical decision regarding the best course of care is individualized for each patient.

Two other key findings emerged from both phases of the 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 do not consider a patient's Intellectual Disability as sufficient reason to withhold cancer screening, and clinicians do not have a routine protocol for providing care, including recommending cancer screening, to patients with Intellectual Disabilities. Rather, clinicians indicated that they consider multiple patient

characteristics prior to recommending screening, regardless if their patients have an Intellectual Disability. Second, primary care providers appear to be aware of the most recent guidelines for cancer screening, and incorporate these guidelines into their clinical practice. For example, clinicians in the present study were aware that Canadian guidelines advise against screening mammography in women under 50 and cervical cancer screening in women under 21. In addition, clinicians in this study appear to apply these current guidelines to all age-eligible patients, including patients with Intellectual Disabilities.

An additional consideration when reviewing the results of this study is that in healthcare there is an increasing focus on health professionals considering patients' needs when deciding on a course of care. In this care paradigm, care is individualized and the patient is granted autonomy in choosing their preferred course of care. Clinicians in the present study appeared to follow this paradigm, in that they reported individualizing care to each patient's needs and respecting patients' autonomy.

In this final chapter, I first integrate the key findings from each phase of the current study. Next, I discuss the limitations, especially methodological limitations, of this study, and how these limitations may have impacted the current study's findings. I then consider three key findings from the study as a whole in relation to what has been ascertained from the previous research. These findings include: the role of attitudes in primary care providers' recommendation for cancer screening to patients with Intellectual Disabilities; the changing nature of cancer screening guidelines and its effect on clinical practices; and the way in which primary care providers deliver care, especially cancer screening, to patients with Intellectual Disabilities. I then conclude the chapter with suggestions for areas of future study, and the main conclusions derived from this study.

Integrating Both Phases and Their Results

The purpose of choosing a convergent mixed methods design was because it was thought that the findings from the qualitative phase would help place the quantitative findings into the clinical context. The quantitative phase found that one key factor, primary care participants' attitudes towards people with Intellectual Disabilities, predicts whether they anticipate recommending breast and colorectal cancer screening to fictional patients with Intellectual Disabilities. Younger participants in the quantitative phase generally had more positive attitudes towards the community inclusion of people with Intellectual Disabilities relative to older participants. Qualitative phase participants were younger, and this may account for them having more positive attitudes, relative to older clinicians. These attitudes may have led to these participants stating their belief that they would provide the same level of care to patients with Intellectual Disabilities as they would to any other patient.

In the qualitative phase, many of the participants considered Intellectual Disabilities to be insufficient reason to withhold cancer screening to any given patient. Rather, they recognized that patients have multiple needs that must be considered prior to a recommendation for screening. While some participants noted that some patients with Intellectual Disabilities may have additional needs, they acknowledged that, for the most part, these needs could be accommodated in order that patients with Intellectual Disabilities receive age-appropriate screening. It is unclear whether participants' inclusive attitudes towards people with Intellectual Disabilities contributed to them stating that they would not hesitate to recommend cancer screening to patients with Intellectual Disabilities who have additional care needs.

In this study, a key consideration is the contribution of both attitudes and experience to participants' anticipated cancer screening recommendations. In the quantitative phase, younger

primary care participants had more positive attitudes, and generally participants with more positive attitudes were more likely to recommend cancer screening. It is possible that younger participants with more positive attitudes had less experience providing care to people with Intellectual Disabilities, while older and more experienced participants may have been more aware of the nuances of recommending cancer screening to this population. Likewise, participants in the qualitative phase generally had positive attitudes and less experience, and thus anticipated that they would not hesitate to recommend cancer screening to patients with Intellectual Disabilities. The responses of residents in the qualitative phase may not reflect real-world situations. It is possible that in clinical settings, more experienced physicians may be more hesitant to recommend cancer screening to age-appropriate screening, because they may be more mindful of the challenges of recommending cancer screening to patients with additional needs.

Limitations of the Current Study

There were a number of limitations, mainly methodological, associated with this study. First, the quantitative phase of the study had a low response rate, and the qualitative phase employed convenience sampling. To increase response rates in the survey, an electronic version of the survey was sent to students and residents, which I thought would be preferred by this group; while mailed paper copies were sent to physicians anticipating that this method might be more convenient for practicing professionals. In spite of these steps, response rates to the survey were still low. Thus, it is probable that the samples in both phases may have been biased, because it is likely that responders had both positive attitudes towards people with Intellectual Disabilities and a special interest in the study topic. Given the resources available, it would have been difficult to recruit participants in a way that may have been less biased, for example recruiting participants as part of a class or continuing education session. In addition, it is possible

that participants in both phases experienced a social desirability bias and gave the responses that they felt were expected by the researcher. Had I been able to include a measure of social desirability bias, I may have been better able to control for this factor.

Given these considerations, the response rate for the quantitative phase was lower than I would have preferred as a result of both the convenience sampling conducted and the resources available. Although I did collaborate with the educational institutions providing training for both family physicians and nurse practitioners, had I devised a more robust recruitment strategy, such as offering more incentives for study participation, or working with the licensing body, the College of Family Physicians of British Columbia, to distribute and endorse the survey, it is possible that the response rates to both phases would have been higher. Previous reviews of studies in which researchers mailed surveys to physicians have typically had higher response rates (e.g., Edwards et al., 2002; Kellerman & Herold, 2001), although these studies frequently had surveys sent directly from medical organizations, they had multiple points of contact with physicians, or they included an incentive, such as a gift card, with the initial survey. It is possible that had I the resources to offer incentives such as gift cards, response rates in my study would have been higher. Also, had I more resources to contact physicians multiple times, it is possible response rates would have been higher. However, given the information available from the College directory, it was difficult to identify which physicians might be more interested in participating if approached multiple times, thus justifying additional resources for recruitment.

An additional limitation related to the sample was lack of nurse practitioner participation in the interview portion of the study; with limited numbers of nurse practitioner students completing the survey. Thus nurse practitioner's perspectives were not considered to the fullest possible extent. Nurse practitioners were not included in the qualitative phase data collection

because no nurse practitioner responded to my survey invitation, and no nurse practitioner students were included in the qualitative phase data collection because, while 9 nurse practitioner students responded to my survey, in the interests of preserving participant anonymity I did not gather any contact information from students.

Second, while the majority of quantitative phase respondents were highly experienced, the majority of interviews in the qualitative phase were conducted with residents who had relatively little clinical experience. This was mainly due to recruitment challenges, and the study would have been more rigorous if more experienced clinicians had also agreed to be interviewed. Because it was found in the quantitative phase that attitudes differed by age group of the participants, a sample that included older experienced physicians completing the interviews would have allowed for more comparative interpretations. Because qualitative phase participants were generally residents, they had less clinical experience providing care to patients with Intellectual Disabilities; thus the data generated in this phase may not be as rich as if more experienced clinicians had taken part.

An additional limitation related to participants' ages is that information regarding participants' ages was gathered categorically, because it was thought that this method would increase participants' confidentiality, and also reduce the amount of missing data for this variable. Related to this, the decision to collect age information from the participants categorically and not continuously created a limitation in the quantitative data analysis, in that the lack of granularity may have obscured a relationship between age and practice behaviors.

An additional limitation is related to the measures used in the quantitative phase. With the benefit of hindsight, it seems that the CLAS-ID was potentially not the most precise

measurement for use in the present study, and that other attitude measures might have been more appropriate. I anticipated that positive aspects of attitudes would more closely predict cancer screening recommendations, and the CLAS-ID is the best instrument to capture these aspects of attitudes. However, I discovered that only aspects of negative attitudes predicted screening, leading to the possibility that a different measure that captures more negative aspects of attitudes might have captured more detailed information.. In particular, the Mental Retardation Attitudes Inventory-Revised (MRAI-R) by Antonak et al. (1994) might have been a more appropriate measure, because this instrument measures multiple aspects of negative attitudes towards people with Intellectual Disabilities.

Also, the unexpected results regarding cervical cancer screening in the written vignettes, in that this screening test was less recommended than other screening tests, may have been due to an oversight in which the patients presented in the vignettes were below the minimum age in the Canadian guidelines. I had purposely chosen younger patients in the vignettes to make it more credible that they still lived at home with their families, but I inadvertently set the patients' age in the cervical cancer screening vignette below the national recommended level. Given that participants in the qualitative phase stated they were generally more familiar with national guidelines than with provincial guidelines, which differed with respect to key details such as age recommendations, it is possible that participants in the quantitative phase may also have been more familiar with national guidelines and thus may have been more hesitant to recommend cervical cancer screening to the younger patients in the vignettes. If the quantitative phase instruments had been pilot tested with the intended study population (primary care providers) rather than with graduate students, I could have avoided issues with the applicability of the cancer screening vignettes in respect to the ages of the patients in the vignettes. Specifically, had

clinicians reviewed the vignettes prior to distributing the survey, they may have recommended that I increase the ages of the patients in the cervical cancer screening vignettes.

An additional limitation related to the written vignettes is that I only offered two vignettes per type of cancer screening, and I presented limited information in the vignettes. Had I presented more information regarding factors shown to be related to cancer screening disparities, such as marital status and socioeconomic status, I may have been better able to control for these factors in participants' anticipated likelihood of recommending screening. Also, had I presented an additional vignette to help control for some of these factors, this may have influenced participants' responses.

Taken together, these limitations do not invalidate the results, although caution must be taken when interpreting them, and especially when generalizing the present study's results to other contexts. This study had a relatively small number of participants in both phases, and the findings related to how cancer screening programs are organized in BC may not be transferable to other jurisdictions, especially jurisdictions in which cancer screening is organized differently. Also, given the limited clinical experience of the qualitative phase participants, and the lack of extensive pilot testing of the quantitative phase instruments, this study's findings may have limited applicability beyond the special case of the clinical scenarios described in the quantitative phase of the present study.

Relating the Key Findings to the Previously Published Research

A key consideration for both phases of this study was how participants' attitudes and their level of clinical experience interacted to influence how they responded to the scenarios presented in the surveys and interview guides. In addition to this finding, this study has three key

findings that are relevant to our understandings based on previously published research. First, it appears that some aspects of primary care providers' attitudes were related to anticipated screening recommendations in certain hypothetical scenarios. In the qualitative phase, participants had more positive attitudes and reported that they would not hesitate to recommend cancer screening to patients with Intellectual Disabilities, although this may not reflect what takes place in the real-world setting. Additionally, it appears that clinicians are very familiar with the current national cancer screening guidelines, and are aware that guidelines change over time, although this may be an artifact of how recently participants completed their medical training, especially participants in the qualitative phase of this study. Finally, it appears that clinicians individualize care decisions, including those pertaining to screening, in order to decide on the best course of care for each patient, regardless of whether the patient has an Intellectual Disability.

Utility of understanding attitudes in relation to primary care providers' cancer screening recommendations

The current study specifically examined whether primary care providers' attitudes towards individuals with Intellectual Disabilities predicted whether they anticipated recommending cancer screening to hypothetical patients presented in vignettes. The quantitative phase results revealed that participants' attitudes do predict anticipated cancer screening recommendations in certain hypothetical scenarios, indicating that at times attitudes may influence certain forms of anticipated clinical behaviour.

The qualitative phase findings revealed that attitudes are likely only one of a myriad of factors that can potentially influence a primary care provider's decision whether or not to recommend cancer screening in any individual case. The key determinant of screening behaviour

appears to be the clinician weighing the evidence-based guidelines against their own clinical judgement to determine which course of care will be recommended for each patient. Clinicians' attitudes may influence this decision-making process, and may determine whether a clinician recommends cancer screening to any individual patient. Previous research, notably by Llewellyn et al. (2011) and Swaine et al. (2013), described reports of individuals with Intellectual Disabilities being told by experienced health professionals that cancer screening is not necessary for women with Intellectual Disabilities. It appears that clinicians in these studies had negative attitudes towards the inclusion of people with Intellectual Disabilities in cancer screening programs, and these attitudes influenced their lack of cancer screening recommendations.

Another key finding was that age was the main variable related to attitudes, as measured by the Community Living Attitudes Scale-Intellectual Disabilities version (CLAS-ID). Previous research has yielded mixed results as to whether age of respondents is related to their attitudes towards people with disabilities. For example, Dorji and Solomon (2009) administered a Chinese translation of the Scale of Attitudes Towards Disabled Persons (Chan, 1984) to 170 physicians and nurses, and found that attitudes varied by age, with younger participants having fewer misconceptions regarding people with disabilities, relative to older participants. In contrast, Matziou et al. (2009) administered the Attitudes Towards Disabled Persons Scale (ATDP) by Yuker (1960) to male and female nurses, and found no difference by age of participants.

One reason for these mixed findings could be the age range of the participants in these studies. In the Matziou et al. (2009) study, the mean age of participants was 24.6 years (SD=9.3), while in the Dorji and Solomon (2009) study, the mean age was 33.4 years (SD=8.03). In the present study, participants' exact ages were not collected. However, approximately 54% of the qualitative phase participants were older than 35 years, and approximately 7% were older than

65 years. Thus, the present study appears to have included a sample of primary care providers with an older age range relative to the previous studies. The inclusion of older participants may have led to greater variability in attitudes, increasing the likelihood of finding an effect for age in the analyses.

An additional consideration for the findings related to attitudes is that the gender of the participants and their previous experience with people with Intellectual Disabilities appeared to not be associated with their attitudes around Intellectual Disabilities. This may reflect the fact that the sample of physicians who participated in the quantitative phase was approximately 50% male and 50% female, while in previous studies the samples were mainly female. In addition, relative to previous studies, the current study's participants generally had more prior work and personal experience with people with Intellectual Disabilities. Previous studies did report that both gender of respondents and their experience with people with Intellectual Disabilities were related to attitudes. Ouellette-Kuntz et al. (2003) and Jones et al. (2008) found many differences between male and female respondents' attitudes as measured by the CLAS-ID. In addition, Sahin and Akyol (2010), Tervo et al. (2004), and Ouellette-Kuntz et al. (2012) found differences in attitudes according to respondents' previous experience with people with disabilities. The current had a less homogenous sample with regards to gender, prior personal and work experience with people with Intellectual Disabilities, and especially age, relative to earlier studies. Because the range of ages was so large, this may have resulted in most differences with attitudes being attributed to age, and this factor may have masked the more subtle differences in attitudes due to gender of participants and previous experience of participants.

Finally, given that most participants in the qualitative phase were medical residents and younger in age, it is possible that they had generally positive attitudes towards the community

inclusion of people with Intellectual Disabilities. These potentially positive attitudes may have led them to anticipate that they would not hesitate to recommend cancer screening to patients with Intellectual Disabilities, and that their patient's Intellectual Disability would be only one of many individual factors that they would consider prior to recommending screening. Many of these participants indicated that they had never had the experience of recommending cancer screening to age-eligible patients with Intellectual Disabilities. Their lack of experience with this clinical scenario may have also contributed to them anticipating that they would recommend cancer screening to patients with Intellectual Disabilities.

Researchers have demonstrated that one key determinant of an individual's future behaviour is their past behaviour (Ouellette & Wood, 1998). Specifically, Danner, Aarts, and De Vries (2008) demonstrated that past behaviour is best predictive of future behaviour when the behaviour is infrequent or complicated in some way, such as might be the case with recommending cancer screening to patients with Intellectual Disabilities. However, in consideration of predicting an individual's future behaviour when the individual has limited prior experience with the behaviour, such as the residents in the qualitative phase, attitudes towards the behaviour have been understood to be a key determinant of future behaviour (Ajzen & Fishbein, 1977; Kraus, 1995). Hence, interviewees' general attitudes towards people with Intellectual Disabilities, rather than their experience, may have had a greater influence on their responses regarding cancer screening.

Thus, this study found that aspects of primary care providers' attitudes towards people with Intellectual Disabilities may predict how they anticipate recommending cancer screening to patients with Intellectual Disabilities in hypothetical scenarios. However, given the findings from the qualitative phase, it is likely other factors also contribute to the process of deciding which

course of action is in the best interests of each individual patient. Additionally, while participants in the qualitative phase generally responded that they would not hesitate to recommend cancer screening to patients with Intellectual Disabilities, their ages and levels of experience may have affected their responses, leading them to anticipate they would promote cancer screening more universally than may be the case in real-world scenarios.

Primary care providers' knowledge of, and application of, evidence-based cancer screening guidelines.

It was not an aim of the present study to determine whether primary care providers adhere to cancer screening guidelines. However, during the interviews, one topic that was explored was how participants proceed to apply cancer screening guidelines as part of routine care. This phenomenon was explored especially with regards to the shifting evidence base for different forms of cancer screening, and consequently the evolving nature of the guidelines. Once again, participants' more recent undergraduate education may have made them more aware of the current cancer screening guidelines, and the shifting application of these guidelines in clinical practice.

At the time of data collection, the BC Cancer Agency (BCCA), which holds responsibility for the coordination of cancer care strategy across all settings in the province of British Columbia, had different guidelines for cancer screening relative to national guidelines. For example, until 2016 the BCCA had specified no minimum age for cervical cancer screening, unlike the national guidelines, which set a minimum age of 21. I had anticipated that primary care providers would be more likely to apply provincial guidelines in clinical practice, rather than national guidelines. However, participants indicated that primary care providers were generally more knowledgeable regarding the Canadian Task Force on Preventive Health Care

(CTFPHC, 2011) guidelines, and were less familiar with British Columbia Cancer Agency's (BCCA, 2016) 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. (Since the qualitative phase data collection for this study was conducted, the BCCA has introduced a minimum age of 25 for cervical cancer screening). Second, participants stated they would exercise caution and discourage women under the age of 50 from obtaining routine screening mammograms. While the BCCA guidelines have recently been changed to no longer encourage screening mammography for average risk women under 50, the CTFPHC guidelines have advised against screening in women under 50 for several years. Thus, in this instance as well, study participants seemed more likely to ground their decisions in national rather than provincial guidelines.

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 were aware of the recent research questioning the benefits of screening mammography, even for women over 50. 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. Thus, participants had not changed their screening mammography recommendations, because health organizations' screening guidelines had not changed since the publication of this new research.

Thus, it appears that while participants are aware of the recent publication of studies questioning the value of comprehensive screening mammography programs, 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. This study

determined that primary care providers are aware of these changing guidelines, and change their screening recommendation practices accordingly. In addition, unlike oncology specialists, primary care providers 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.

Primary care providers accommodating patients with Intellectual Disabilities' needs with regards to cancer screening.

Participants indicated that they are aware of the need for screening in individuals with Intellectual Disabilities, and that they would accommodate patients with Intellectual Disabilities' needs with regards to screening. Specifically, participants indicated they would take extra time during an appointment to explain the nature and need for screening to patients with Intellectual Disabilities, if the participants felt this education was necessary. This may reflect participants' limited clinical experience, both with providing care to individuals with Intellectual Disabilities, and their limited experience working in a clinical setting with multiple time pressures. A second consideration is that the participants in the interviews likely had positive attitudes towards the community inclusion of people with Intellectual Disabilities, and it is likely these attitudes biased their responses to be more enthusiastic regarding promoting screening

Previous research, mainly concerning breast cancer screening, indicated that many health professionals felt they had insufficient knowledge regarding women with Intellectual Disabilities' needs for breast cancer screening. However, they felt they had sufficient knowledge regarding screening in the general population (Hanna et al., 2011; Kirby & Hegarty, 2010; McIlpatrick et al., 2011; Tyler et al., 2010). Self-advocates (women with Intellectual Disabilities; Parish et al., 2012; Truesdale-Kennedy et al., 2011; Wilkinson, Deis et al., 2011) also indicated

that they felt they had insufficient knowledge regarding breast cancer screening. The present study's finding, that primary care providers' knowledge that cancer screening is important for women with Intellectual Disabilities and that they anticipated that they would take extra time during an appointment to educate people with Intellectual Disabilities regarding cancer screening, may reflect that these participants had more positive attitudes towards cancer screening than have been found in prior studies. Alternatively, this finding may reflect the current study participants' lack of experience providing care to individuals with Intellectual Disabilities. Having never been in the situation where they had to educate people with Intellectual Disabilities concerning their need for cancer screening, they may not have recognized the implications of what they were concluding relative to the time investment or the reimbursement options for that additional time.

A final consideration regarding how participants provide care in a general sense to individuals with Intellectual Disabilities 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 made it clear that they weigh a multitude of factors, including but not limited to a patient's Intellectual Disability and any associated needs, prior to deciding the optimal course of care for each patient.

Previous research appears to indicate that there are specific characteristics of care that primary care providers should employ when providing care to this population. For example, Baumbusch, Phinney, and Baumbusch (2014) and Wullink, et al. (2009) interviewed individuals with Intellectual Disabilities, and found that participants described certain styles of patient-physician communication that they find helpful in clinical encounters. Similarly, Wilkinson, Dreyfus, Bowen, and Bokhour (2013) interviewed both patients with Intellectual Disabilities 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 Disabilities expressed a desire for physicians to provide medical information in plain language, without using complex medical jargon. These studies implied that individuals with Intellectual Disabilities want care delivered in a way similar to other individuals with Intellectual Disabilities. 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 Disabilities, and they therefore feel they ought to individualize care to each patient, whether the patient has an Intellectual Disability or not.

Thus the motivation of these clinicians to individualize care may reflect their positive attitudes towards the community inclusion of people with Intellectual Disabilities. They would promote cancer screening to all of their patients, perhaps not realizing the nuances of providing care to patients with Intellectual Disabilities. 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 likely had positive attitudes and were enthusiastic regarding screening, more experienced physicians, in addition to having less positive attitudes, may also be more aware of the difficulties and demands in providing primary care to patients with Intellectual Disabilities.

Suggestions for Further Research

First of all, while the quantitative phase of this study focused on a single factor -- attitudes towards people with Intellectual Disabilities -- and its relationship to primary care providers' decision to recommend cancer screening to patients with Intellectual Disabilities, the findings from the qualitative phase indicate that multiple factors are at play in a clinicians'

decision to recommend or not recommend cancer screening. Also, given that the majority of participants in this study had positive attitudes, this finding raises the possibility that prioritizing clinician attitudes toward people with Intellectual Disabilities as a singular focus for future research may not be the best approach to resolving inequities, as it is likely that multiple other factors also contribute to cancer screening recommendations by primary care providers.

While there may be limited value in continuing to examine attitudes in isolation in relation to cancer screening recommendations, further research may be needed to explore experienced primary care providers' experiences recommending cancer screening to patients with Intellectual Disabilities more broadly. This study's participants in the qualitative phase had limited experience providing care to patients with Intellectual Disabilities, and this lack of experience may have affected their responses in the interviews. Further research is needed to determine if clinicians experienced in providing care to age-eligible patients with Intellectual Disabilities may be more hesitant to recommend cancer screening to patients with Intellectual Disabilities, and the extent to which they may be willing to accommodate any additional needs patients may have with respect to screening

Finally, the findings of this study appear to indicate that primary care providers are well aware of the current cancer screening guidelines and the shifting evidence base for these guidelines. Additionally, clinicians incorporate these guidelines into their clinical practice. However, many of the participants in this study, especially in the qualitative phase, were residents and were thus recent graduates of medical school. Thus, it is likely they were more recently educated regarding the updated guidelines than more experienced physicians. Further research may be needed to determine if more experienced and established primary care providers are as fully aware of the changing nature of cancer screening guidelines, or as sensitive to the

implications of the evolving evidence base from which they are derived. If these studies were to find that older practicing physicians are less aware of the evolving nature of these guidelines, it would suggest that more continuing medical education may be needed to make established primary care providers aware of changing cancer screening guidelines and their applicability to clinical practice.

Conclusions

In summary, this study explored the role of primary care providers' attitudes, specifically their attitudes towards the community inclusion of people with Intellectual Disabilities, in contributing to the clinical decision to recommend or not recommend cancer screening. Previous research had suggested that attitudes may play a role in this decision, although no previous study had specifically focused on the role of attitudes in the wider context of primary care practitioners' perceptions of how they determine screening recommendations for individuals with Intellectual Disabilities. This study revealed that, although in some circumstances attitudes may contribute to the clinician's decision to recommend screening, the decision to recommend cancer screening to any patient may be better understood as a complex decision, with attitudes representing only one factor. It is likely that, where primary care providers decide not to recommend cancer screening to any given patient with Intellectual Disabilities, factors such as patient preference, assessment of individualized needs, interpretation of eligibility according to standardized guidelines, recognition of the fluidity of the evolving evidence for screening, and even practical matters such as the physical location and arrangement of the practice facility play a role in contributing to the decision as to whether or not to recommend various cancer screening options.

Attention to the possibility that negative attitudes disadvantage the quality of care that persons with Intellectual Disabilities receive remains a worth focus of consideration. In this study, despite an attempt to explore for such attitudes using multiple methodological approaches, no significant negative attitudes were detected. The suggestion that younger care providers are more positive in their attitudes and more committed to an individualized approach to patient care, as seemed to be the case in this study, may reflect an optimistic trend with respect to movement toward equity for this population. Although, given the relatively restrictive range of attitudes measured in the present study, evidenced by the small variation in the sample, it is possible that while these differences were statistically significant, they may not be sufficiently large to noticeably impact clinicians' behavior in the clinical setting. Consequently, while the quantitative phase found that some aspects of attitudes predict anticipated likelihood of recommending cancer screening, the qualitative phase revealed that the decision to recommend screening is complex, and in the clinical setting, differences in attitudes may not be large enough to have a measurable effect.

However, whether cancer screening rates can serve as a legitimate proxy for judging primary care equity for certain populations remains uncertain. Cancer screening recommendations may be sufficiently complex, especially as the evidence evolves, that assumptions based on population screening rates may misrepresent what clinicians are actually taking into consideration as they determine the best approach to care for their patients. As cancer screening guidelines evolve on the basis of new and emerging evidence, it will be important to ensure an ongoing capacity to reflect critically on equity issues. It is possible that future research exploring how individuals with Intellectual Disabilities access care, specifically how they face issues related to equity, might be best to examine other forms of preventive care in which

guidelines are not changing to the same extent as cancer screening guidelines. It is also possible that the findings in the present study would also be related to how individuals with Intellectual Disabilities access other forms or preventive care.

Although the results of this study were inconclusive as to whether care provider attitudes about persons with Intellectual Disabilities disadvantage them with respect to cancer screening, ongoing attention to the question of equitable care for all persons seems a core value that was clearly evident in the population under study. One hopes that this value will continue to drive research toward uncovering and resolving barriers to such equitable care.

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APPENDIX A: Quantitative Phase Instruments

Trainees' demographic questionnaire

1) Profession

- family medicine resident
- nurse practitioner student
- Other (please specify)

If you selected other, please specify

2) Have you practiced in a health profession prior to your current program?

- Yes
- No

3) If yes, please specify the profession:

4) How many years did you practice this profession?

5) Gender:

- Male
- Female
- Other (please specify)

If you selected other, please specify

6) Age:

- 25 or less
- 26-35
- 36-45
- 46-55
- 56-65
- Older than 65

7) Do you have any training specific to working with people with Intellectual Disabilities?

- Yes
- No

8) If yes, please describe:

9) Do you have any friends or family members who have Intellectual Disabilities?

- Yes
- No

10) If yes, please describe the nature of the relationship

11) Do you have any previous work experience specific to working with people with Intellectual Disabilities?

- Yes
- No

12) If yes, please describe

Professionals' demographic questionnaire

1) Profession

- family physician
- nurse practitioner
- Other (please specify)

2) How many years have you practiced your profession?

- 0-5 years
- 6-10 years
- 11-15 years
- 16-20 years
- more than 20 years

3) Gender:

- Male
- Female
- Other (please specify)

If you selected other, please specify

4) Age:

- 25 or less
- 26-35
- 36-45
- 46-55
- 56-65
- Older than 65

5) Do you have any training specific to working with people with Intellectual Disabilities?

- Yes
- No

6) If yes, please describe:

7) Do you have any friends or family members who have Intellectual Disabilities?

- Yes
- No

8) If yes, please describe the nature of the relationship

9) How many patients with Intellectual Disabilities do you typically see over a year?

- 0-3 patients
- 4-8 patients
- 9-15 patients
- more than 15 patients

10) Would you consider your practice to have a significant portion devoted to people with Intellectual Disabilities?

- Yes, definitely
- Yes, somewhat
- No, most of my patients do not have Intellectual Disabilities
- I do not have patients with Intellectual Disabilities as part of my practice

11) Do you have any previous work experience specific to working with people with Intellectual Disabilities?

- Yes
- No

12) If yes, please describe

Community Living Attitudes Scale

13) People with intellectual disabilities are happier when they live and work with others like them.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

14) People with intellectual disabilities trying to help each other is like "the blind leading the blind".

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

15) People with intellectual disabilities should not be allowed to marry and have children.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

16) A person would be foolish to marry a person with an intellectual disability.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat

- 5 = Agree moderately
- 6 = Agree strongly

17) People with intellectual disabilities should be guaranteed the same rights in society as other persons.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

18) People with intellectual disabilities do not want to work.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

19) People with intellectual disabilities need someone to plan their activities for them.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree somewhat

20) People with intellectual disabilities should not hold public office.

- 1 = Disagree strongly
- 2 = Disagree mode
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

21) People with intellectual disabilities should not be given any responsibility.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

22) People with intellectual disabilities can organize and speak for themselves.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

23) People with intellectual disabilities do not care about advancement in their jobs.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

24) People with intellectual disabilities do not need to make choices about the things they will do each day.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

25) People with intellectual disabilities should not be allowed to drive.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

26) People with intellectual disabilities can be productive members of society.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

27) People with intellectual disabilities have goals for their lives like other people.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

28) I would trust a person with an intellectual disability to be a baby sitter for one of my children.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

29) People with intellectual disabilities cannot exercise control over their lives like other people.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

30) People with intellectual disabilities can have close personal relationships just like everyone else.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

31) I would not want to live next door to people with intellectual disabilities.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

32) People with intellectual disabilities are usually too limited to be sensitive to the needs and feelings of others.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

33) People with intellectual disabilities should live in sheltered facilities because of the dangers of life in the community.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

34) People with intellectual disabilities should be encouraged to lobby legislators on their own.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

35) People with intellectual disabilities are the best people to give advice and counsel to others who wish to move into community living.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

36) The opinion of a person with an intellectual disability should carry more weight than those of family members and professionals in decisions affecting that person.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

37) People with intellectual disabilities can plan meetings and conferences without assistance from others.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

38) People with intellectual disabilities can be trusted to handle money responsibly.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

39) Residents have nothing to fear from people with intellectual disabilities living and working in their neighborhoods.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

40) People with intellectual disabilities usually should be in group homes or other facilities where they can have the help and support of staff.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

41) Sheltered workshops for people with intellectual disabilities are essential.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

42) The best care for people with intellectual disabilities is to be part of normal life in the community.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

43) Most people with intellectual disabilities prefer to work in a sheltered setting that is more sensitive to their needs.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

44) Without some control and supervision, people with intellectual disabilities could get into real trouble out in the community.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

45) The rights of people with intellectual disabilities are more important than professional concerns about their problems.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

46) Agencies that serve people with intellectual disabilities should have them on their boards.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

47) The best way to handle people with intellectual disabilities is to keep them in institutions.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

48) Homes and services for people with intellectual disabilities should be kept out of residential neighborhoods.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

49) Increased spending on programs for people with intellectual disabilities is a waste of tax dollars.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

50) Homes and services for people with intellectual disabilities downgrade the neighborhoods they are in.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

51) Professionals should not make decisions for people with intellectual disabilities unless absolutely necessary.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

52) People with intellectual disabilities are a burden on society.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat
- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

Cancer Screening Vignettes

53) Jane is a fifty-seven year old woman with a mild Intellectual Disability who has no chronic health problems. She lives with her husband, and they have no children. Jane is a regular patient who comes to see you about a skin condition on her hand that you diagnose as eczema. When asked, Jane says that she has never had a mammogram. Jane has a first cousin who was diagnosed with breast cancer five years ago. How likely is it that you would recommend that Jane obtain a mammogram?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely
- 5 = Somewhat likely
- 6 = Very likely

54) Susan is a fifty-eight year old woman with type two diabetes which is controlled with diet and exercise, and no other chronic health problems. She lives with her husband, and they have no children. Susan is a regular patient who comes to see you about a skin condition on her hand that you diagnose as eczema. When asked, Susan says that she has never had a mammogram. Susan has a first cousin who was diagnosed with breast cancer five years ago. How likely is it that you would recommend that Susan obtain a mammogram?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely
- 5 = Somewhat likely
- 6 = Very likely

55) Madison is a twenty-year old woman with a mild Intellectual Disability. Madison lives with her parents, and works part-time at a local grocery store. Madison is a new patient, and she comes to see you about obtaining prescription medication for her acne. Madison mentions she has a boyfriend, and mentions that she is sexually active, but when asked, reports that she has never had a Pap smear. How likely is it that you would recommend that Madison obtain a Pap smear?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely

- 5 = Somewhat likely
- 6 = Very likely

56) Sarah is a nineteen-year old woman who received a kidney transplant at age eight. Sarah lives with her parents, and works part-time at a local grocery store. Sarah is a new patient, and she comes to see you about obtaining prescription medication for her acne. Sarah mentions she has a boyfriend, and mentions that she is sexually active, but when asked, reports that she has never had a Pap smear. How likely is it that you would recommend that Sarah obtain a Pap smear?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely
- 5 = Somewhat likely
- 6 = Very likely

57) Elaine is a sixty-five year old woman with a mild Intellectual Disability. She is retired and volunteers at a nearby elementary school. Elaine is a regular patient, and she comes to see you for her annual check-up. When asked, she reports that she has never had a fecal occult blood test to check for colorectal cancer. How likely is it that you would recommend that Elaine obtain a fecal occult blood test?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely
- 5 = Somewhat likely
- 6 = Very likely

58) Debbie is a sixty-five year old woman with mild rheumatoid arthritis which is controlled with medication. She is retired and volunteers at a nearby hospital. Debbie is a regular patient, and she comes to see you for her annual check-up. When asked, she reports that she has never had a fecal occult blood test to check for colorectal cancer. How likely is it that you would recommend that Debbie obtain a fecal occult blood test?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely

- 5 = Somewhat likely
- 6 = Very likely

59) Bob is a sixty-six year old man with a mild Intellectual Disability. He is retired and volunteers with Special Olympics. Bob is a regular patient, and he comes to see you for advice about starting an exercise program. When asked, he reports that he has never had a fecal occult blood test to check for colorectal cancer. How likely is it that you would recommend that Bob obtain a fecal occult blood test?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely
- 5 = Somewhat likely
- 6 = Very likely

60) Dave is a sixty-five year old man with mild asthma which is controlled with medication. He is retired and volunteers with Special Olympics. Dave is a regular patient, and he comes to see you for advice about starting an exercise program. When asked, he reports that he has never had a fecal occult blood test to check for colorectal cancer. How likely is it that you would recommend that Dave obtain a fecal occult blood test?

- 1 = Very unlikely
- 2 = Somewhat unlikely
- 3 = Slightly unlikely
- 4 = Slightly likely
- 5 = Somewhat likely
- 6 = Very likely

61) The researchers conducting this study are also conducting an interview study, to understand primary care providers' experiences recommending cancer screening to individuals with Intellectual Disabilities. If you would like to receive information about the study, please provide your email address and phone number below. Providing this information does not mean you agree to be in the study: instead you will receive information about the study, and can decide whether to participate at a later date.

Email address:

62) Phone number (including area code):

Thank you for completing our survey!

APPENDIX B: Qualitative Phase Interview Guide

Thank you for agreeing to take part in this interview. If at any time there is any question that you would rather not answer or discuss, just let me know. Also, all identifying names (such as hospital names, place names) will be removed when the audio is transcribed and given a numerical code, and the answers to the questions will not be reported in any way that might identify you, your location, your patients, or your colleagues. The interview will likely take 30-60 minutes, but you may stop at any time, and if you need to leave before you have finished answering all the questions, and if you would like to continue at another time, we can reschedule.

Questions concerning family practice

1. Please describe your practice, including the type of patients in your practice, and the community you practice in.
2. Possible prompts to encourage elaboration:
3. What type of community do you practice in (urban, suburban, small town, rural)?
4. How long have you practiced there? Have you practiced in general?
5. What type of patients do you typically treat (seniors, people with disabilities, children)?

Questions Concerning Intellectual Disabilities and Cancer Screening

1. There are different ways of defining Intellectual Disabilities, depending on the profession or discipline. How would you define or describe Intellectual Disabilities?
2. How would you describe the range of abilities in patients with Intellectual Disabilities that you have seen as part of your practice?
3. As a family practice resident, what do you feel is your role in providing primary care to individuals with Intellectual Disabilities? As a family physician, what do you feel is your role in promoting cancer screening to all patients? For your patients with Intellectual Disabilities, do you feel your role in promoting cancer screening would be different in any way? If so, how?
4. Now I'm going to specifically ask about different types of cancer screening. For these questions, it may be useful to have the vignettes of hypothetical patients in front of you,

as a memory aid. However, the focus of the next section is more general than just the vignettes that were used in the survey study.

Screening Mammography

1. Recently, there has been debate, including in the media, concerning whether the benefits of screening mammography outweigh the risks, mainly the risks of over-diagnosis and over treatment. However, the majority of Canadian health organizations did not change their screening mammography guidelines. Are you aware of this controversy? Did this debate change how you promote screening mammography to your patients?
2. What factors do you consider when recommending screening mammography?
 - a. (Possible prompts to encourage elaboration) Do you consider:
 - i. Personal and family history (including age)
 - ii. Lifestyle
 - iii. Time and practice constraints
 - iv. Accessibility of screening through the healthcare system
3. If a patient has an Intellectual Disability, do you take different factors into consideration? If so, how?
4. Please tell me about a time you recommended screening mammography to a patient with Intellectual Disabilities. What factors did you consider when making the recommendation?

Cervical cancer screening

1. At what age do you typically recommend Pap smears to your female patients (not just those with disabilities)?
2. When recommending a Pap smear, what other factors do you consider before recommending a Pap smear?
 - a. (Possible prompts to encourage elaboration) Do you consider:
 - i. Patient's history of sexual activity
 - ii. Patient's lifestyle factors
 - iii. Time and practice constraints

- iv. Accessibility of follow-up care if a patient has a positive result
3. If a patient has an Intellectual Disability, do you take different factors into consideration? If so, how?
4. Please tell me about a time you recommended a Pap smear to a patient with Intellectual Disabilities. What factors did you consider when making your recommendation?

Colorectal cancer screening

1. Currently, the Canadian Task Force on Preventive Health Care recommends a two-step process for screening for colorectal cancer in those aged 50 and up at average risk of developing colorectal cancer: the first step is a fecal occult blood test or fecal immunohistological test, followed by a colonoscopy if a patient has a positive result. However, there are different protocols in other countries. In your experience, what is your colorectal cancer screening recommendation for your patients at average risk for colorectal cancer?
2. What factors do you consider when recommending a colorectal cancer screening test to average-risk individuals in the recommended age range?
 - a. (Possible prompts to encourage elaboration) Do you consider:
 - i. Personal and family history, including patient's sex
 - ii. Lifestyle factors
 - iii. Time and practice constraints
 - iv. Accessibility of follow-up care for positive results
3. For patients with Intellectual Disabilities who are within the eligible age range, would you consider different or additional factors? What are those factors?
4. Please tell me about a time you recommended colorectal cancer screening to a patient with Intellectual Disabilities. What factors did you consider when making your recommendation?

Conclusion

1. Is there anything else you'd like to add or comment on about what we discussed today?
2. Is there anything else you'd like to add or comment on about cancer screening?
3. Is there anything else you'd like to add or comment on about the care of individuals with Intellectual Disabilities?

4. Is there anything you'd like to add or comment on about the postal survey you completed prior to the interview?
5. Do you know of a colleague who may be interested in learning more about this interview study? If so, I will email you a new copy of the invitational letter and consent information, which you may forward to your colleague.

Thank you very much for your time today.

APPENDIX C: Consent Form for Quantitative Phase

Primary Care Providers' Attitudes and Experiences Concerning Recommending Cancer

Screening to Individuals with Intellectual Disabilities

I. STUDY TEAM

Principal Investigator:

Sally Thorne, PhD, RN, DSc (Hon), FAAN, FCAHS,
Professor,
UBC School of Nursing
T213 2211 Wesbrook Mall
Vancouver, BC
Canada V6T 2B5
Phone: 604-822-XXXX

Co-Investigator(s):

Genevieve Breau, MA,
PhD Candidate,
Interdisciplinary Oncology Program,
Faculty of Medicine,
University of British Columbia
Email: XXXX@XXX.CA

Jennifer Baumbusch, PhD, RN,
Assistant Professor,
UBC School of Nursing
Phone: 604 822-XXXX

This research is being conducted in partial fulfillment of the requirements for the degree of Doctor of Philosophy for Ms. Breau. Results from this study will be published in Ms. Breau's dissertation project, and the completed dissertation will be made available within UBC cIRcle.

II. SPONSOR

The study is being partially funded through grant monies provided by the Interdisciplinary Oncology Program, Faculty of Medicine, UBC.

III. INVITATION AND STUDY PURPOSE

- You are being invited to take part in this research study because you are a nurse practitioner or a family physician practicing within BC.
- We want to learn more about how primary care providers, such as yourself, recommend cancer screening to people with Intellectual Disabilities. This study will help us learn more about factors influencing primary care providers' decisions whether to recommend cancer screening to patients with Intellectual Disabilities.
- We are doing this study to learn more about how primary care providers decide to recommend cancer screening to people with Intellectual Disabilities.

IV. STUDY PROCEDURES

If you say 'Yes', here is what participation entails:

- We will ask you about the likelihood you would recommend cancer screening to people with Intellectual Disabilities.
- We will give you a form with questions to answer. This form has three parts: first is a demographic form which asks about your experience working with people with Intellectual Disabilities; the second is the Community Living Attitudes Scale-Intellectual Disabilities form; and the third part presents a series of vignettes about hypothetical patients, and asks you to rate the likelihood you would recommend cancer screening to each patient.
- Completing the questionnaire will take approximately 15 minutes. You may stop answering questions at any time.
- Completing the questionnaire is voluntary. You may choose to not participate. Your colleagues will not know whether or not you have participated, and they will not know what your answers are.
- The UBC Voivici Enterprise Feedback Management System. The company's servers are located within Canada. It complies with the BC Freedom of Information and Protection of Privacy Act.
- At the conclusion of the questionnaire, you will have the option of providing your name and contact information if you are interested in receiving more information (invitation letter and consent form) for an additional interview study being conducted by the same investigators. Providing this information is completely voluntary, and requesting more information does not mean you agree to take part in the study. You will only need to decide whether you wish to take part in the additional study after reviewing the additional study information.

V. STUDY RESULTS

- The results of this study will be reported in a doctoral dissertation and will also be submitted for publication in peer-reviewed journals. Presentations based on this research may also be given at academic conferences.
- A summary of the results of this study will be given to the professional associations for distribution to their members.

VI. POTENTIAL RISKS OF THE STUDY

- We do not think there are any direct harms from participating in this study. You may refuse to answer any question for any reason, such as finding a question to be too upsetting or personal. Please let one of the study investigators or BREB staff know if you have any concerns.
- Some of the questions we ask may seem sensitive or personal. You do not have to answer any question if you do not want to.
- We will not be asking for your name, and we will not report demographic data (such as age or gender) in a way that someone might be able to identify you. You may choose to not answer any question.
- Your professors and supervisors will not know whether you participated, and will not know what your answers were.

VII. POTENTIAL BENEFITS OF THE STUDY

We do not think taking part in this study will directly benefit you. However, in the future, other health professionals may benefit from what we learn in this study.

VIII. CONFIDENTIALITY

- All documents will be identified only by code number and kept in a locked filing cabinet at UBC. Subjects will not be identified by name in any reports of the completed study. Demographic data will not be reported in any way that would inadvertently identify participants.
- Electronic documents will be kept on a password protected computer, and only the principal investigator and co-investigators will have access to the original study data.
- If you provide your name and contact information, this will be kept separate from your responses, and your name and contact information will not be linked to your responses.

IX. PAYMENT

- We will not provide an honorarium for participating in this study. Participating in the study is completely voluntary.

X. CONTACT FOR INFORMATION ABOUT THE STUDY

If you have any questions or concerns about what your participation requires, please contact the principal investigator or one of the co-investigators. The names and telephone numbers or email addresses are listed at the top of the first page of this form.

XI. CONTACT FOR COMPLAINT

- If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-XXXX or if long distance e-mail XXXX@XXXX.CA or call toll free 1-877-822-XXXX.

XII. PARTICIPANT CONSENT

If the questionnaire is completed, it will be assumed that consent has been given. Completing the questionnaire is completely voluntary and up to you.

APPENDIX D: Consent Form for Qualitative Phase

Primary Care Providers' Attitudes and Experiences Concerning Recommending Cancer Screening to Individuals with Intellectual Disabilities-Interview Study

I. STUDY TEAM

Principal Investigator:

Sally Thorne, PhD, RN, DSc (Hon), FAAN, FCAHS
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T213 2211 Wesbrook Mall
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Co-Investigator(s):

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Faculty of Medicine,
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Jennifer Baumbusch, PhD, RN,
Assistant Professor,
UBC School of Nursing
Phone: 604 822-XXXX

This research is being conducted in partial fulfillment of the requirements for the degree of Doctor of Philosophy for Ms. Breau. Results from this study will be published in Ms. Breau's dissertation project, and the completed dissertation will be made available within UBC cIRcle.

II. SPONSOR

The study is being partially funded through grant monies provided by the Interdisciplinary Oncology Program, Faculty of Medicine, UBC.

III. INVITATION AND STUDY PURPOSE

- You are being invited to take part in this research study because you are a physician practicing family medicine in BC or a nurse practitioner practicing in BC.
- In the previous 3 years you have provided general health care to at least one patient with Intellectual Disabilities.
- We want to learn more about how primary care providers, such as yourself, recommend cancer screening to people with Intellectual Disabilities. This study will help us learn more about factors influencing primary care providers' decisions whether to recommend cancer screening to patients with Intellectual Disabilities.
- We are doing this study to learn more about how primary care providers decide to recommend cancer screening to people with Intellectual Disabilities.

IV. STUDY PROCEDURES

If you say 'Yes', here is what participation entails:

- If you are interested in participating in the study, a research assistant will obtain written consent from you via email, and answer any questions you may have.
- You will be asked a series of questions concerning your experiences recommending cancer screening, both to your patients in general, and also specifically to patients with Intellectual Disabilities.
- The entire interview will take no more than an hour. You may decide to no longer participate at any time. The interview will also be audio recorded. The audio recording will be kept on a password protected computer, and the audio files on the digital recorder will be deleted once files are transferred to the computer.

V. STUDY RESULTS

- The results of this study will be reported in a doctoral dissertation and will also be submitted for publication in peer-reviewed journals. Presentations based on this research may also be given at academic conferences.
- You may ask to receive a summary of the study results at the conclusion of the study. If you wish to receive the results summary, please indicate so when you provide written consent via email.

VI. POTENTIAL RISKS OF THE STUDY

- We do not think you will experience any harms while participating in this study. If you find a question upsetting or overly personal, you may refuse to answer it. Please let one of the study investigators or BREB staff know if you have any concerns.
- We will not be including your name in the interview transcript, and we will not report demographic data (such as age or gender) in a way that someone might be able to identify you. You may choose to not answer any question. We will also remove all identifying information contained in the interview transcript (such as patient names, other health professional names, hospitals and health clinics, and geographic locations).

VII. POTENTIAL BENEFITS OF THE STUDY

We do not think you will directly benefit by participating in the current study. However, in the future, other health professionals may benefit from what we learn in this study.

VIII. CONFIDENTIALITY

- All transcripts will be identified only by code number and kept in a locked filing cabinet at UBC. Subjects will not be identified by name in any reports of the completed study. Demographic data will not be reported in any way that would inadvertently identify participants.
- Electronic documents will be kept on a password protected computer, and only the principal investigator and co-investigators will have access to the original study data.

IX. PAYMENT

- As a token of appreciation, all participants will receive a \$25 Starbuck gift card.

X. CONTACT FOR INFORMATION ABOUT THE STUDY

If you have any questions or concerns about the study and your participation, please contact the principal investigator or one of the co-investigators. The names and telephone numbers or email addresses are listed at the top of the first page of this form.

XI. CONTACT FOR COMPLAINT

- If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-XXXX or if long distance e-mail XXXX@XX.CA or call toll free 1-877-822-XXXX.

XII. PARTICIPANT CONSENT

- Taking part in this study is completely voluntary. You have the right to refuse to participate in this study at any time. If you decide to participate, you may choose to withdraw at any time without giving a reason and without any negative impact on your professional practice.
- If you wish to participate, please email the research assistant for this study who provided you with the consent information, and in the body of the email indicate you have reviewed this consent information and agree to voluntarily participate. Also please provide your email signature (electronic signature is sufficient) in the body of the email. The research assistant will then contact you concerning participating in the study.
- In addition, if you wish to receive the results of the study, please indicate so in your email.
- Alternatively, you may complete the consent information on the last page of this document (see below) and fax this page to (604) 822-XXXX, ATTN: Genevieve Breau.

Thank you for taking the time to review this consent information.

XII. PARTICIPANT CONSENT

- Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your professional practice.
- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.
-

Participant Signature

Date

Printed Name of the Participant signing above

Yes, I would like to receive a summary of the study results.