

PATIENT EXPERIENCES FOR THYROID CANCER SURVIVORS  
TRANSITIONING FROM CANCER TREATMENT TEAMS TO PRIMARY CARE

by

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Dalhousie University is located in Mi'kma'ki, the  
ancestral and unceded territory of the Mi'kmaq.  
We are all Treaty people.

## **DEDICATION PAGE**

For my family, who have been with me every step of the way.

## TABLE OF CONTENTS

LIST OF TABLES.....	v
LIST OF FIGURES.....	vii
ABSTRACT .....	viii
LIST OF ABBREVIATIONS AND SYMBOLS USED.....	ix
ACKNOWLEDGEMENTS .....	x
CHAPTER 1 INTRODUCTION .....	1
CHAPTER 2 LITERATURE REVIEW AND RATIONALE .....	4
2.1 Conceptual Framework for Cancer Survivorship Care Needs.....	4
2.2 Survivorship Care Needs for Cancer Survivors Within the Transition Phase .....	7
2.3 Thyroid Cancer Survivorship in Canada.....	11
2.4 Challenges Associated with Transitioning DTC Survivors to Primary Care Led Follow-up .....	14
CHAPTER 3 OBJECTIVES.....	17
3.1 Research Aim.....	17
3.2 Research Question.....	17
3.3 Hypothesis.....	17
3.4 Objectives.....	18
CHAPTER 4 METHODOLOGY.....	19
4.1 Introduction.....	19
4.2 Study Methods.....	20
DTC Survivors (Primary Data Collection) .....	20
Other Cancer Survivors (Comparative Sample) .....	21
4.3 Study Instrument .....	25
4.4 Study Variables .....	30
4.5 Analysis .....	37
Descriptive Analyses.....	37
Power Calculation .....	40
Sensitivity Analyses .....	40
CHAPTER 7 DISCUSSION.....	83
7.2 Strengths and Limitations.....	91

7.4 Implications.....	96
7.5 Conclusions .....	98
BIBLIOGRAPHY .....	99
APPENDIX A SAMPLE OF MODIFIED CANCER TRANSITION SURVEY.....	115

## LIST OF TABLES

Table 1	Inclusion and Exclusion Criteria for DTC Survivor Sample (Adapted from Imran et al. 2019).....	19
Table 2	Inclusion and Exclusion Criteria for Adult and AYA Cohorts of the 2016 Experiences of Cancer Patients in Transition Study .....	22
Table 3	Inclusion and Exclusion Criteria for Adult Cohort of the 2016 Experiences of Cancer Patients in Transition Study by Disease Site, ICD-O codes and Timeframe .....	22
Table 4	Subheadings for Original 2016 Cancer Transition Survey with Associated Question Items and Summary of Questions .....	26
Table 5	List of Variables with Corresponding Survey Item Number and Categorization .....	31
Table 6	Descriptive Analysis of Demographic Variables in DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors <sup>1</sup> .....	47
Table 7	Descriptive Analysis of Disease Related Variables in DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors <sup>1</sup> .....	51
Table 8	Descriptive Analysis of Treatment Related Variables in DTC Survivor Sample .....	55
Table 9	Descriptive Analysis of Needs Within the Physical Domain for DTC Survivors .....	56
Table 10	Descriptive Analysis of Needs Within the Emotional Domain for DTC Survivors .....	57
Table 11	Descriptive Analysis of Needs Within the Practical Domain for DTC Survivors .....	59
Table 12	Descriptive Analysis of Needs Within the Practical Domain for Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	60
Table 13	Descriptive Analysis of Needs Within the Emotional Domain for Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	61
Table 14	Descriptive Analysis of Needs Within the Practical Domain for Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	61

Table 15	Descriptive Analysis of Seeking Help and Unmet Needs Within the Physical Domain for DTC Survivors .....	63
Table 16	Descriptive Analysis of Seeking Help and Unmet Needs Within the Emotional Domain for DTC Survivors.....	65
Table 17	Descriptive Analysis of Seeking Help and Unmet Needs Within the Practical Domain for DTC Survivors.....	66
Table 18	Descriptive Analysis of Unmet Informational Needs for DTC Survivors.....	67
Table 19	Cross Tabulation of Frequency with Severity of Needs in DTC Sample .....	68
Table 20	Cross Tabulation of Frequency of Needs in DTC Survivors with if Respondents Had Difficulty Obtaining Help.....	70
Table 21	Cross Tabulations for Individuals' Needs with Prevalence of Presence with Associated Pearson $\chi^2$ Test Statistics for DTC Survivors and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	72
Table 22	Cross Tabulations for Individuals Needs with Prevalence of Unmet Needs with Associated Pearson $\chi^2$ Test Statistics for DTC Survivors and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	77
Table 23	Descriptive Analysis of Demographic Variables Age Categories and Gender for All Potential Survey Participants Sent a Research Package .....	79
Table 24	Cross Tabulation of Proportion Endorsing Fatigue in DTC Survivors with Years After Diagnosis .....	80

## LIST OF FIGURES

Figure 1	Conceptual Framework for CPAC Transitions Study, adapted from (Fitch et. al 2019) .....	28
Figure 2	Age Distribution of DTC Survivor Sample ( $n=202$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1514$ ) .....	43
Figure 3	Gender Distribution of DTC Survivor Sample ( $n=202$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1514$ ) .....	44
Figure 4	Highest Level of Education Attained by DTC Survivor Sample ( $n=200$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1461$ ) .....	45
Figure 5	Annual Household Income Distribution of DTC Survivor Sample ( $n=198$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1445$ ) .....	46
Figure 6	Population Size of Residence Distribution of DTC Survivor Sample ( $n=196$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1454$ ) .....	47
Figure 7	Proportion of Respondents Endorsing Physical Needs from DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	74
Figure 8	Proportion of Respondents Endorsing Emotional Needs from DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	75
Figure 9	Proportion of Respondents Endorsing Practical Needs from DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors .....	76

## ABSTRACT

**Background:** Despite the increasing incidence of differentiated thyroid cancer (DTC), mortality has remained relatively stable. Given the need for lifelong surveillance, there is interest in transitioning low-risk DTC survivors to primary care. A recent pan-Canadian study showed that survivors of other cancers consistently report several unmet physical and psychosocial needs. However, the specific needs of DTC survivors remain unknown.

**Objectives:** 1) To describe the self-reported physical, emotional, practical and informational needs of low-risk DTC survivors in Nova Scotia during the transition period to primary care and 2) To examine if low-risk DTC survivors are equally likely to report physical, emotional, practical and informational needs during the transition period compared to breast cancer, colorectal cancer, prostate cancer, melanoma and hematologic cancer survivors.

**Methods:** This is a cross-sectional multiple methods design using the 83 item “Cancer Transition Survey”. The study protocol is based upon the national Experiences of Cancer Patients in Transition Study. The “Cancer Transition Survey” was administered in 2023 to adult patients with low-risk DTC diagnosed between 2006 to 2020, who had either been discharged or were ready for discharge from the Halifax Interdisciplinary Thyroid Oncology Clinic to primary care. Survey data from DTC survivors was compared to population-based data from other cancer survivors previously surveyed as part of the national study.

**Results:** There were a total of 205 respondents from the 375 potential participants who met prespecified inclusion/ exclusion criteria (54.6% response rate). The majority of respondents in the DTC sample were female ( $n=164$ , 81.2%), aged 55-74 ( $n=114$ , 56.4%) and had received surgery ( $n=174$ , 86.1%). The most common posttreatment needs reported were fatigue (81.3%), anxiety/fear of recurrence (69.5%) and depression/low mood (46.3%). There was a significant difference in the proportion of respondents endorsing fatigue in the DTC sample compared to other cancer survivors from the Nova Scotia cohort of the Experiences of Cancer Patients in Transition Study (81.3% vs 64.3%,  $\chi^2 = 22.5412$ ,  $p$ -value = 0.00).

**Conclusion:** This is the first study to assess the supportive care needs of DTC survivors transitioning to primary care within Canada. We found that fatigue is significantly more common in DTC survivors compared to other cancer survivors. Further work is needed to appropriately optimize the healthcare service models targeting this population in Nova Scotia based on these study findings.

**Word Count: 376**

## LIST OF ABBREVIATIONS AND SYMBOLS USED

AJCC	American Joint Committee on Cancer
AYA	Adolescent and Young Adult
CCS	Canadian Cancer Society
COVID-19	Coronavirus Disease 2019
CPAC	Canadian Partnership Against Cancer
DTC	Differentiated Thyroid Cancer
HRQoL	Health Related Quality of Life
ICD-O	International Classification of Diseases for Oncology
ITOC	Interdisciplinary Thyroid Oncology Clinic
PCP	Primary Care Provider
PROM	Patient Reported Outcome Measures
QoL	Quality of Life
RAI	Radioactive Iodine-131
SCP	Survivorship Care Plan
TSH	Thyroid Stimulating Hormone

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## CHAPTER 1 INTRODUCTION

Thyroid cancer has one of the most rapidly rising incidence rates among cancers in developed countries (1,2), specifically amongst young women, who constitute the largest single group of thyroid cancer patients (3,4). In 2023, the Canadian Cancer Society (CCS) reported that thyroid cancer was the most common type of cancer diagnosed nationally in individuals aged 15-29 years old, and the second most common cancer type for individuals aged 30-49 years old (5). An analysis of the Canadian Cancer Registry from 2016 revealed that age-standardized incidence rates of thyroid cancer since 1970 had risen from 1.5 per 100,000 to 7.2 per 100,000 in men, and from 3.9 per 100,000 to 23.4 per 100,000 in women (6). This global phenomenon of rapidly rising thyroid cancer incidence rates (7,8) has been termed the “thyroid cancer epidemic” (2,6,9,10). While incidence rates have recently plateaued or slightly decreased in many countries (11,12), the sheer number of new thyroid cancer cases remains a significant public health concern (13,14).

Despite the increasing incidence rates, the overall mortality from thyroid cancer in Canada has remained stable, with a 5-year net survival rate of nearly 98% (6,12). The now well-accepted explanation for this seeming contrast is the frequent use of ultra-sensitive imaging modalities (2,15,16) driving the overdiagnosis of small, well-differentiated tumors which would have likely otherwise remained subclinical if left untreated (17). Globally, most new cases of thyroid cancer are papillary

thyroid cancer (6,18), which is the most common subtype in the group of thyroid cancers called *differentiated thyroid cancer* (DTC) (12). In comparison to other histological forms of thyroid cancer that are more aggressive, such as anaplastic (19) and medullary thyroid cancer (20), DTC is rarely complicated by distant metastases (21) and thus carries an excellent prognosis (22). While DTC has a very high survival rate, data from the United States National Institute of Health's Surveillance, Epidemiology and End Results Program database between 1975 and 2013 shows that the rates of metastatic and complex papillary thyroid cancer have risen by 2.9% annually (22). This suggests that the rise in global number of new cases of DTC should not be dismissed as simply attributable to overdiagnosis alone (5), and underscores the importance of further evaluating the public health impact of rising incidence rates for this cancer subtype.

Currently, more than 1,500 DTC patients in Nova Scotia are managed by a multidisciplinary team of healthcare professionals at the Interdisciplinary Thyroid Oncology Clinic (ITOC) located in Halifax, Nova Scotia. The ITOC team includes a Radiation Oncologist, an Endocrinologist, and specialist nurses alongside dedicated administrative support. Due to the increasing incidence of DTC and the overall low mortality rates, there is an increasing number of cancer survivors at the clinic who have successfully transitioned from the active oncologic care phase to a long-term surveillance phase. Up until recently, all patients at the ITOC were being followed indefinitely for long-term management after their initial cancer treatment. With increasingly limited healthcare resources and the uniquely

advantageous position of primary care to provide long-term, holistic patient-centered care, there has been a keen interest in transitioning low-risk DTC survivors who have remained disease free for a defined time-period to the community for ongoing surveillance and management.

A 2019 multi-center, retrospective study led by the ITOC team demonstrated that primary care follow-up of patients with low-risk thyroid cancer was both feasible and associated with lower healthcare costs when compared with follow-up in tertiary care centers (23). Consequently, the ITOC team initiated a discharge policy for low-risk DTC survivors to primary care. While primary care-led long-term follow-up has been demonstrated to be safe for this population (24), challenges remain in comprehensively supporting DTC survivors during this transition phase. A recent pan-Canadian study showed that many other cancer survivors transitioning to primary care and completing oncologic treatment consistently report several unmet physical and psychosocial needs (25). However, as DTC survivors were not included in this national study, their specific unmet needs during this vulnerable post-treatment transition period remain unknown.

## CHAPTER 2 LITERATURE REVIEW AND RATIONALE

### 2.1 Conceptual Framework for Cancer Survivorship Care Needs

The term “cancer care” encompasses a broad spectrum of interdisciplinary services that range across the lifetime of a patient including primary prevention, diagnosis, active management and follow-up care (26,27). Individuals who have been diagnosed with cancer, regardless of the course of their disease, are commonly referred to as “cancer survivors” within the health literature (28), although not all individuals who have experienced cancer identify with the term (29). In Canada, the incidence rates of cancer continue to rise, with almost one in two Canadians expected to have a diagnosis of cancer in their lifetime (30). Alongside this, however, due to improved diagnostic procedures and treatment modalities (31,32), survival rates for most major cancer types are at historical highs (30,33,34). As a result, the CCS estimated that in 2018 there were more than 1.5 million people alive in Canada who had previously been diagnosed with cancer, representing an increase of more than 500,000 people over the decade prior (35).

It is now well understood that cancer survivors continue to have cancer-related physiological and psychosocial concerns well after their diagnosis and treatment (36–38). Originally described by Mullan in 1985 (39), this period after cancer diagnosis is commonly referred to as the “survivorship phase”. The “survivorship phase” is then further subdivided into several “seasons” of survivorship

encompassing the acute phase immediately post-diagnosis, all the way up until end-of-life care (40). Recently, there has been an increased focus on addressing the long-term sequelae associated with cancer treatment, including cognitive symptoms and toxicities (41). These can be divided as either *long-term* effects, if they started during treatment and then persisted, or *late* effects, if they started after treatment was completed. However, in many instances, it can be difficult to classify a symptom as either a late or long-term effect as there is often ambiguity around when symptoms begin, and if they were truly associated with the cancer treatments (42).

While traditional measures for quality of cancer care tend to emphasize clinical outcomes, there has been increasing recognition about the importance of assessing quality indicators from a patient-centred perspective (43–45). Here, the overwhelming focus is on meeting an individual's particular health care needs (46), rather than the medical treatment alone. *Patient-reported outcomes*, which are “any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else”, allow for capturing of the subjective experience of an individual who is experiencing the illness (47). As a result, *patient reported outcome measures* (PROMs) are particularly effective at capturing the concept of the “patient experience” (48,49). While there is no standardized definition, the current literature on “patient experiences” acknowledges that this is a complex, multifaceted concept that values a patient's perspective of their health, their

disease, and their experience of healthcare services (50). Previous work has shown that the concept of “patient experience” is more specific than simply general measures of satisfaction (51), and the use of PROMs is commonly accepted and recognized as an important dimension of the quality of care within patient-centred health care systems (52).

With improved treatments and higher survival rates for most major cancer types, there has been increasing interest in understanding the “transition” phase of cancer survivorship (53). While there is no standardized definition or timeframe, the accepted understanding within the cancer survivorship literature is that the transition phase marks the period of when the delivery of cancer care shifts from active treatment to longer-term care (55). In its seminal 2006 report “*From Cancer Patient to Cancer Survivor: Lost in Transition*”, the Institute of Medicine emphasized the delivery of high quality cancer survivorship care posttreatment, including surveillance for the late medical and psychosocial effects related to cancer and cancer treatments (54). The release of this report marked a major shift in cancer care research, resulting in a greater emphasis on assessing the burden of cancer survivorship from a patient-centred perspective (37,55,56)

Bringing forward this understanding that cancer continues to have broad and adverse physical and psychosocial effects after treatment (57), one way of better addressing these concerns using a patient-centred perspective (58) is through the *Supportive Care Needs Framework* (44,59). “Supportive care needs” is

recognized to be a broad concept, which has previously been defined as “needs which lack the level of service or support an individual perceives is necessary to achieve optimal well-being” (60,61). The *Supportive Care Needs Framework* conceptualizes that individuals diagnosed with cancer will experience psychosocial distress and can have a wide range of care needs outside of medical interventions within several domains (e.g., physical, emotional, practical, spiritual and informational) (59). Several studies have been done within the Canadian context validating this conceptual framework, with cancer survivors continuing to endorse various unmet needs (62). The framework serves to guide healthcare professionals and policy makers when implementing screening strategies and individualizing interventions aimed at reducing distress for cancer survivors.

## **2.2 Survivorship Care Needs for Cancer Survivors Within the Transition Phase**

While several national Canadian cancer organizations have released guidelines building on the Institute of Medicine’s original recommendations to implement high quality survivorship care specifically during the transition phase, uptake has been slow and inconsistent (63,64). One barrier within Canada has been the wide variability of follow-up models used, and the lack of coordination within health care systems (65). Both the Canadian Partnership Against Cancer (CPAC) and Cancer Care Ontario recommend a primary care-led or a shared care model

of follow-up care, as opposed to an oncologist-led model. This is because the primary care-led model is associated with lower healthcare costs per visit, more appropriate test-utilization, lower use of emergency services and has been demonstrated to be as safe as oncologist-led models of care (83).

Despite these apparent advantages, primary care providers (PCPs) have consistently remained hesitant to take on further cancer survivorship care in Canada, citing concerns with the re-referral processes, inadequate communication with oncologists, and a lack of comfort and training on cancer surveillance guidelines (56,66). To address these concerns, there is growing attention to help foster the leadership role of PCPs in the successful transition of cancer care through the development of harmonized and evidence-based surveillance guidelines. While there is evidence that cancer survivors with a PCP receive more preventative care than those without (67), PCPs continue to report a lack of suitable resources (66,68,69) and limited confidence in the management of cancer survivorship related concerns (70).

Another major barrier in the transitioning of cancer survivors to a primary care-led follow up model has historically been that cancer survivors themselves are very hesitant to move away from oncologist-led models of follow-up care, despite warning signs that this practice is not sustainable from a systems perspective. From a patient-centred perspective, the transition phase of cancer survivorship presents unique and ever-evolving challenges. Previous studies have shown that

cancer survivors characterize this period as one of insecurity (71), reporting issues accessing care (72), difficulty communicating with their providers (73) and distress from unmet care needs (74). Furthermore, many survivors report being unaware of existing resources and feeling unsupported (75), with historically underserved rural and Indigenous populations also reporting compounding financial and geographic barriers in accessing survivorship care services (64). While *survivorship care plans* (SCP) have been promoted as a means of promoting patient empowerment, their uptake and quality has been inconsistent (76) and its efficacy in promoting better patient-reported outcomes has been heavily disputed (77).

Despite the recognition of survivorship challenges during the transition to primary care, very few studies in Canada have assessed the needs of cancer survivors during this phase of cancer survivorship, with early studies being limited by scope and not specifically evaluating patient experiences (25). In response to this gap within the cancer survivorship literature, the CPAC conducted the 2016 Experiences of Cancer Patients in Transition Study (“Transitions Study”), which remains the most comprehensive study done within Canada to-date on the experiences of cancer survivors’ post-treatment. The Transitions Study used a cross-sectional population-based survey design, gathering provincial leads from all ten Canadian provinces who oversaw survey administration and data collection, and the data were then pooled at a national level. The results of the Transitions Study revealed that cancer survivors of all types in Canada continue

to have consistently unmet psychosocial and physical needs, including concerns with sexual function, fatigue and fear of recurrence (25,78,79). Concerningly, of those who sought help for their unmet needs, nearly one-third reported having difficulty obtaining help or did not find help (80).

Subgroup analysis from the Nova Scotia cohort also showed that cancer survivors' needs differed depending on their primary cancer diagnosis and the treatment received (81). For example, the most common concerns reported from prostate cancer survivors were issues with sexual function and intimacy; however, blood and breast cancer survivors reported more concerns with fatigue and fears of recurrence. Additionally, there was a wide variety of follow-up cancer care models reported by respondents in Nova Scotia, with nearly 20% reporting they were exclusively seen by their PCP and 40% reporting a shared care model. Importantly, this national study did not include DTC survivors, and therefore, the psychosocial and physical needs in the transition period to community care specific to this population have not yet been characterized, nor is it known how they would compare to other cancer survivors.

A variety of other factors have also been shown to be associated with unmet supportive care needs. Disease-related factors associated with more unmet needs include the presence of medical comorbidities (82), primary cancer type, and advanced cancer stage (61,83). Several patient characteristics have also been shown to be associated with the presence of unmet needs, including

gender, age, whether their primary residence is within a rural or urban location, marital status, self-reported ethnic minority status, and living within a socioeconomically deprived area (61,83,84). Recently, a study using data from the Nova Scotia cohort of the CPAC Transitions Study found that other demographic factors including immigration status, education, employment status, access to a patient navigator and internet use were all significantly associated with the presence of unmet psychosocial needs within this population (85). Other possible influencers of psychosocial needs assessed within this study included health literacy, household income, and time since the end of treatment.

### **2.3 Thyroid Cancer Survivorship in Canada**

DTC is the most commonly diagnosed group of thyroid cancers, which consists of both papillary and follicular cancer subtypes (86). Despite the rising incidence, five-year net survival has remained excellent at approximately 98% since the 1990s in Canada (12), resulting in ever-increasing numbers of DTC survivors. Importantly, these survivors face several unique and long-term challenges post-cancer treatment. DTC survivors treated with total thyroidectomy and/or radioactive iodine-131 (RAI) require lifelong biomarker surveillance, including thyroglobulin testing (87), and thyroxine hormone replacement post-surgical treatment (88), all of which has been linked to increased psychological stress (89). Thyroid hormone replacement is typically given as oral levothyroxine therapy (88). Generally, DTC survivors require frequent dose-adjustments of oral

levothyroxine replacement to target specific ranges of thyroid stimulating hormone (TSH) intended to reduce the risk of recurrence (90). This means that for many survivors, their TSH levels may be intentionally suppressed and outside of reference range. The suppression of TSH within DTC survivors is associated with several potential long-term adverse consequences (91), including impaired bone health (92), cardiovascular disease (93) and menstrual irregularities (94).

The need to target specific TSH ranges that may be outside the normal reference range is also associated with some other challenges when counselling DTC survivors. In the clinical experience of the ITOC team, DTC survivors frequently question the adequacy of their thyroid hormone replacement, and often attribute ongoing physical and psychosocial needs to thyroid hormone replacement concerns. This observation has been previously reported within the thyroid cancer survivorship literature (95), and highlights an important area of concern for DTC survivors that is not captured in current thyroid cancer-specific health related quality of life (HRQoL) measures (96).

It is well-established within the literature that despite the relatively lower mortality rates of thyroid cancer, DTC survivors continue to experience a wide variety of unmet physical needs after treatment, contributing to consistently lower scores on quality-of-life (QoL) instruments compared to the general population (97). These include postoperative concerns such as dysphonia and dysphagia (98), symptoms specific to thyroid hormone dysfunction such as temperature

intolerance and palpitations (99,100), as well as more non-specific symptoms including fatigue, muscle cramps (101–103) and worsened cognitive function (104).

A unique consideration in the care of DTC survivors is that they are usually younger in comparison to other cancer survivors (105). Surprisingly, initial findings from the North American Thyroid Cancer Survivorship Study have found that DTC survivors report worse overall QoL scores compared to survivors of other cancers that have poorer mortality outcomes (i.e. breast cancer and colorectal cancer), and that a younger age at DTC diagnosis was associated with worse QoL scores (106). One explanation for this apparent paradox is that DTC survivors have a longer duration of survivorship burden (97). An additional unique feature of DTC survivors affecting the management of these patients is the prevalence of women of reproductive age (107). Given reported associations between RAI and both decreased ovarian reserve (108) as well as live birth rates (109), counselling about the fertility implications of treatment is another important consideration in the long-term care of these survivors.

The importance of screening for psychosocial distress in this population is well documented, given the consistent evidence for anxiety (110), fear of recurrence (111) and relationship challenges (112) that has been demonstrated.

Concerningly, however, there is some evidence to suggest that DTC survivors still feel unsupported when it comes to these concerns and feel invalidated by

healthcare providers who suggest that the disease is a “good cancer” in comparison to other cancer types (113). Additionally, DTC survivors also report several unmet informational and practical needs post-treatment (114–117), including financial strain (118), how to self-monitor for signs of recurrence and return to work support, which is consistent with evidence for other cancer survivors (57).

#### **2.4 Challenges Associated with Transitioning DTC Survivors to Primary Care Led Follow-up**

While health care costs and feasibility remain important considerations in assessing how to optimally provide follow-up cancer care, another key factor that has not been explored in DTC specifically is cancer survivors’ perspectives and views about their experience of transitioning to primary care. One anticipated barrier in the successful transition of low-risk DTC survivors is distrust of PCPs to manage cancer-related concerns. One Canadian study found that DTC survivors preferred specialist-led, or a shared-care model, compared to an exclusively primary care-led model (119). This preference for specialist-led long-term follow-up is commonly shared by other cancer survivors (120,121). While it is important to incorporate cancer survivors’ preferences into care models to increase their acceptability, there is also consensus that given constrained resources and no evidence showing any differences in recurrence between the care models, further education and support is needed to promote successful care transitions and

promote sustainable cancer-care systems (122). With increasing numbers of DTC survivors in Nova Scotia being soon discharged to exclusively primary care-led follow-up in the future, understanding survivors' experiences and the reasons for their hesitancy with this follow-up model is fundamental to developing and recommending targeted interventions that address these concerns.

Cancer Care Ontario currently recommends that low-risk DTC survivors should be discharged to primary care 5 years after treatment (123). However, in a recent Ontario study surveying 70 endocrinologists, it was found that specialists were hesitant to discharge low-risk DTC survivors mainly due to primary care-related factors (124). These included concerns about whether they could communicate with family physicians and if recommendations would be followed through.

Interestingly, a subsequent study also done in Ontario that assessed the perspective of family physicians found that primary care doctors rated communication and clear recommendations from endocrinologists as the most important factors affecting successful transitions of care (125). These conflicting perspectives show that interdisciplinary communication and cooperation during the transition phase specifically also needs to be improved for successful handover of care of DTC survivors.

Finally, another important aspect of delivering quality care to DTC survivors during the transition period is to address whether specific roles are best carried out by specialists, PCPs or both. Several studies have reinforced the importance

of clear role delineation (126), well-defined cancer care pathways (127,128), and communication of management plans to cancer survivors through SCPs (129). Unfortunately however, PCPs still report a lack of clarity and consensus in the role they play with managing the long term needs of cancer survivors (130), a lack of survivorship care resources and concerns about the time needed to provide survivorship care (68). There is some limited evidence to suggest that providing targeted education to PCPs can increase both provider and patient confidence in cancer care delivery (131,132). However, there is a lack of evidence as to whether such interventions increase the acceptability of primary care-led models for DTC survivors specifically.

## **CHAPTER 3 OBJECTIVES**

### **3.1 Research Aim**

To expand upon the work completed by the CPAC to describe and assess the experiences, perspectives and unmet needs of DTC survivors in Nova Scotia compared to breast cancer, colorectal cancer, prostate cancer, melanoma and hematologic cancer survivors after they have transitioned or are in the process of transitioning from primary cancer care treatment to community-based management and follow-up.

### **3.2 Research Question**

What are the physical and psychosocial needs of DTC survivors who have transitioned or are in the process of transitioning to primary care in Nova Scotia, and how do these compare to the needs of breast cancer, colorectal cancer, prostate cancer, melanoma and hematologic cancer survivors in Nova Scotia?

### **3.3 Hypothesis**

We anticipate that DTC survivors transitioning to primary care are equally likely to report unmet physical and psychosocial needs compared to breast cancer,

colorectal cancer, prostate cancer, melanoma and hematologic cancer survivors in Nova Scotia.

### **3.4 Objectives**

**Objective 1:** To describe the self-reported physical, emotional, practical and informational needs of low-risk DTC survivors in Nova Scotia during the transition period to primary care.

**Objective 2:** To compare the reported physical, emotional, practical and informational needs of DTC survivors during the transition period against breast cancer, colorectal cancer, prostate cancer, melanoma and hematologic cancer survivors in Nova Scotia.

## CHAPTER 4 METHODOLOGY

### 4.1 Introduction

For primary data collection, a modified version of the CPAC 2016 Transitions Study survey was administered to low-risk DTC survivors who met pre-specified inclusion and exclusion criteria (Table 1), which are detailed below. The data were then compared to prior data from the cancer survivors surveyed in the Nova Scotian cohort of the CPAC 2016 Transitions Study.

Table 1 Inclusion and Exclusion Criteria for DTC Survivor Sample (Adapted from Imran et al. 2019)

<b>Cancer Subtype</b>	<b>Time Frame</b>	<b>Inclusions</b>	<b>Exclusions</b>
DTC (papillary and follicular thyroid cancer)	Diagnosed between January 1, 2006, and December 31, 2020	(1) Primary tumour (or largest tumour in the case of multifocal thyroid cancer) <2 cm  (2) AJCC stage I  (3) Undetectable stimulated thyroglobulin 2 years after treatment  (4) Nx, N0, and N1a lymph node status only	(1) Aggressive tumour pathology including evidence of tall cells, columnar cells, and/or a diffuse sclerosing variety

## 4.2 Study Methods

### *DTC Survivors (Primary Data Collection)*

Potential survey participants for the DTC sample were identified by ITOC through their internal database ( $n=375$ ). From the initial list of 385 people, 10 potential participants were excluded due to not residing in Nova Scotia ( $n=3$ ), no valid Nova Scotia address listed ( $n=4$ ), the participant had passed away ( $n=2$ ) and a duplicate name ( $n=1$ ). ITOC provided the list of names and associated contact information to the Principal Investigator who was then responsible for survey distribution, data entry and statistical analyses. The ITOC team maintains a prospectively collected comprehensive computerized registry of all DTC patients seen by the clinic since 2006.

Potential participants included adults above the age of 18 years old at the time of diagnosis, as only adult DTC patients are seen at ITOC. The remainder of survey administration and data collection methodology followed the same protocol as the 2016 Transitions Study, including mixed-mode survey delivery. This included distribution of both a paper-based survey through courier mail and the option to complete the survey online through a personal identification number (PIN) included within the research package. To improve response rates, potential participants received a reminder letter and phone call approximately 28 days after the initial survey mailout. Reminder phone calls were made by a volunteer working at ITOC using a standardized script.

Inclusion and exclusion criteria for the DTC sample were adapted from previous research work published by ITOC to identify low-risk thyroid cancer patients appropriate to transition to primary care for long-term follow-up (23). The only change is that the requirement for patients to have received RAI was removed as per the 2015 ATA guidelines (90), which recommends that post-surgical RAI not be administered for low-risk DTC. All patients who meet inclusion criteria (Table 1) were approached to participate. All potential survey participants were diagnosed with a form of DTC (either papillary or follicular thyroid cancer) between January 1, 2006, and December 31, 2020. Potential participants were diagnosed with a small (<2 cm) stage 1 tumour with minimal lymph node involvement and had undetectable stimulated thyroglobulin levels 2 years after treatment. Thyroid cancer staging was done using the eighth edition of the American Joint Committee on Cancer (AJCC) thyroid cancer staging system (84). DTC survivors with pathological evidence of more aggressive tumour types, including tall cells, columnar cells or survivors or those with a diagnosis of diffuse sclerosing variant of papillary thyroid cancer, were excluded.

#### *Other Cancer Survivors (Comparative Sample)*

Adult cancer survivors including breast cancer, colorectal cancer, prostate cancer, melanoma, hematologic cancer and other cancer survivors within Nova Scotia were surveyed in 2016 as part of the CPAC Experiences of Cancer Patients in Transition Study, for which Dr. Robin Urquhart was the provincial lead. Cancer survivors with non-metastatic disease were surveyed one to three

years after their primary cancer treatment across the country through a cross-sectional, population-based survey (25). The de-identified, raw survey data for the Nova Scotia cohort was provided by Dr Urquhart’s team and used for comparative purposes in the present study. Survey participants from the 2016 comparative group were recruited from the Nova Scotia Cancer Registry using pre-specified inclusion and exclusion criteria, including disease site specific criteria using the International Classification of Diseases for Oncology (ICD- O) topography codes (see Tables 2 and 3, adapted from the CPAC Experiences of Cancer Patients in Transition Study Protocol) (85).

Table 2 Inclusion and Exclusion Criteria for Adult and AYA Cohorts of the 2016 Experiences of Cancer Patients in Transition Study (by Population Characteristics)

<b>Adults</b>	<b>AYA</b>
(1) Diagnosis of non-metastatic breast, colorectal, prostate, melanoma, or hematologic cancer	(1) Diagnosis of any invasive cancer, except: Stage IV at diagnosis (except testicular), non-melanoma skin cancer or Kaposi’s sarcoma
(2) At least 30 years old at diagnosis	(2) Between ages of 18-29 years
(3) 1-3 years after primary treatment ended	(3) 1-3 years after primary treatment ended

Table 3 Inclusion and Exclusion Criteria for Adult Cohort of the 2016 Experiences of Cancer Patients in Transition Study (by Disease Site, ICD-O codes and Timeframe)

<b>Disease Site</b>	<b>Timeframe</b>	<b>Inclusions</b>	<b>Exclusions</b>
Breast	May 2, 2012 to May 2, 2014	(1) ICD-O-3 topography code C50.0 to C50.9 (inclusive)	(1) Stage IV at diagnosis

<b>Disease Site</b>	<b>Timeframe</b>	<b>Inclusions</b>	<b>Exclusions</b>
		(2) Behaviour code = 3 <sup>1</sup>  (3) Female breast cancer cases only	(2) Lymphoma M95 to M98 (inclusive)  (3) Sarcoma  (4) Cases recorded as having died (at time of extraction)
Colorectal	May 2, 2012 to May 2, 2014	(1) ICD-O-3 topography codes: C18.0, C18.2 to C18.9, C19.9, C20.9 and C26.0  (2) Behaviour code = 3 <sup>1</sup>	(1) Stage IV at diagnosis  (2) Lymphoma codes M-95 to M-98 ( <i>inclusive</i> )  (3) Sarcomas  (4) Cases recorded as having died (at time of extraction)
Prostate	May 2, 2012 to May 2, 2014	(1) ICD-O-3 topography code C61.9  (2) Behaviour code = 3 <sup>1</sup>	(1) Stage IV at diagnosis  (2) Cases recorded as having died (at time of extraction)  (3) ICD-O-3 histology codes: 9050-9055, 9140 and 9590-9992
Melanoma	Nov 2, 2012 to Nov 2, 2014	(1) ICD-O-3 topography code C44  (2) ICD-O-3 histology codes 8720 to 8790 (inclusive)  (3) Behaviour code = 3 <sup>1</sup>	(1) Stage IV at diagnosis  (2) Cases recorded as having died (at time of extraction)
Hodgkin's Lymphoma	Aug 2, 2012 to Aug 2, 2014	(1) ≥ 30 years of age at diagnosis  (2) ICD-O-3 histology codes: 9650– 9655,	(1) Hodgkin Lymphoma and Diffuse Large B-Cell Lymphoma: Stage IV (Cotswold Staging System), Stage IV (Ann Arbor Staging System)

<b>Disease Site</b>	<b>Timeframe</b>	<b>Inclusions</b>	<b>Exclusions</b>
		9659, 9661–9665, 9667	or collaborative stage IV at diagnosis  (2) Cases recorded as having died (at time of extraction)
Diffuse B-cell lymphoma	Aug 2, 2012 to Aug 2, 2014	(1) ICD-O-3 histology codes: 9680	
Acute myelogenous leukemia	Aug 2, 2012 to Aug 2, 2014	(1) ≥ 30 years of age at diagnosis  (2) ICD-O-3 histology codes: 9840, 9861, 9865-9867, 9869, 9871- 9874, 9895-9897, 9898, 9910-9911, 9920	
Acute lymphocytic leukemia	May 2, 2010 to May 2, 2012	(1) ≥ 30 years of age at diagnosis (2) ICD-O-3 histology codes: 9826, 9835-9836 (3) For the following histology codes: 9811-9818 and 9837, please apply these topography codes C420, C421 and C424	

1. Behaviour code 3 refers to malignant tumours, as defined by the ICD-O.

In Nova Scotia, the survey was administered to both an adult and an adolescent and young adult (AYA) cohort (85). All respondents were surveyed one to three years after primary cancer treatment, establishing the timeframe of primary

cancer diagnosis within 2010 and 2014. Adult survey participants were 30 years or older at diagnosis with non-metastatic breast cancer, colorectal cancer, prostate cancer, melanoma and hematologic cancers (Hodgkin's lymphoma, diffuse B-cell lymphoma, acute lymphocytic leukemia and acute myeloid leukemia only). Survey participants in the AYA cohort were between 18 to 29 years of age (inclusive) and included survivors with any diagnosis of invasive cancer except Kaposi's sarcoma and non-melanoma skin cancer. All survivors with TNM stage IV cancer or Ann Arbor stage IV lymphoma were excluded, except for testicular cancer for the AYA cohort.

#### **4.3 Study Instrument**

The CPAC pan-Canadian Transitions Study survey ("Cancer Transition Survey") is a mix of 83 open- and closed-ended items grouped under 11 subheadings (Table 4) designed to assess enablers and barriers to desired health systems (25). These include factors such as access to care, education of providers, communication, coordination of care as well as practical supports. The survey is also designed to capture both cross-cutting influencers of needs (e.g., education, household income) as well as the different types of care and supports that survivors utilize to meet their needs, such as medical treatments, counselling, guidance/education. Unmet needs are organized by domains based upon the *Supportive Care Framework* and include physical/symptom burden, emotional/psychosocial, informational and practical domains (see Figure 1).

Table 4 Subheadings for Original 2016 Cancer Transition Survey with Associated Question Items and Summary of Questions

Subheading	Question Items (Inclusive)	Summary of questions
Information about you	1-8	<ul style="list-style-type: none"> <li>• Demographic information including age, gender, overall QoL, household members</li> </ul>
Your health and well-being	9-11	<ul style="list-style-type: none"> <li>• Overall health, other chronic conditions, coping strategies</li> </ul>
About your history with cancer	12-19	<ul style="list-style-type: none"> <li>• Diagnosis, date of diagnosis, treatments received, current regimen</li> </ul>
Health care providers who oversee your follow-up cancer care	20-23	<ul style="list-style-type: none"> <li>• Members of healthcare team in follow-up cancer care, confidence in the healthcare team, use of healthcare services</li> </ul>
Overall experiences of follow-up cancer care	24-33	<ul style="list-style-type: none"> <li>• Perception of quality of services, accessibility of services, sensitivity, communication, usefulness of services from healthcare team.</li> <li>• Perception of coordination between healthcare team members</li> <li>• Main challenges in transition period</li> </ul>

<b>Subheading</b>	<b>Question Items (Inclusive)</b>	<b>Summary of questions</b>
Understanding the changes in your health	34-67	<ul style="list-style-type: none"> <li>• Self-reported changes in physical, emotional and practical domains</li> <li>• How much each change is a concern, if help was sought, how easy to access help</li> </ul>
Access to follow-up cancer care plans and medical records	68-70	<ul style="list-style-type: none"> <li>• Cancer care plan provided, accessibility to medical records</li> </ul>
Health insurance	71-72	<ul style="list-style-type: none"> <li>• Health insurance coverage, options and ease of attaining coverage</li> </ul>
Just a few more questions	73-80	<ul style="list-style-type: none"> <li>• More demographic information including languages spoken, education level, rural/urban, employment</li> </ul>
Internet use	81-82	<ul style="list-style-type: none"> <li>• Frequency of internet use and interaction with cancer related issues on the internet</li> </ul>
Final comments from you	83	<ul style="list-style-type: none"> <li>• Open ended question inviting any other comments</li> </ul>

<b>TYPES OF NEED: (DOMAINS)</b>	<b>Physical/ Symptom Burden</b> (e.g., physical comfort, freedom from pain, cognitive symptoms, fatigue)	<b>Emotional / Psychosocial</b> (e.g., ability to cope, social/family relationships, reassurance)	<b>Information</b> (e.g., information for decision making)	<b>Practical</b> (e.g., needs for assistance in affording and access to care)
<b>INFLUENCERS OF NEED:</b>	<b>Cross-Cutting Influencers</b> (e.g., education, household income, age, health literacy, type of cancer, time since end of treatment, geography (urban/rural))			
<b>TYPES OF CARE/SUPPORT:</b>	<b>Types of care and supports to meet the needs</b> (e.g., medical treatment, counselling, guidance, education)			
<b>ENABLERS AND BARRIERS TO DESIRED HEALTH SYSTEM: (AREAS OF FOCUS)</b>	<b>Access to Care /Support</b> (Location and availability of services ) <b>Training and Education of Providers</b> (Specific to survivorship and follow-up care) <b>Access to Individualized Information</b> (Specific and tailored to individual needs) <b>Communication</b> (Between care providers and patients/survivors) <b>Coordination of Care</b> (Continuity and integration among providers and with patients) <b>Practical supports</b> (Health care services not covered by insurance, transportation, etc.)			

Figure 1 Conceptual Framework for CPAC Transitions Study, adapted from (Fitch et. al 2019)

The Cancer Transition Survey was developed using both the LiveStrong and Cancer Survivors Unmet Needs measures, both of which were reviewed by the survey group and found to have validity in assessing the posttreatment needs of cancer survivors and assess the factors/ personal characteristics of survivors with unmet needs (85). Additions and changes to the Cancer Transition Survey were done through an iterative review process with multiple stakeholder involvement, including subject matter experts and the study design team. Pilot cognitive and performance testing was done with 103 participants to assess

average time of completion, item clarity and identify low performing items (25). The survey was found to take 30-45 minutes on average to complete, and minimal changes were made to the survey content after pilot testing (81). For the present study, a modified version of the Cancer Transition Survey (“Modified Cancer Transition Survey”) was administered to low-risk DTC survivors (Appendix A). Modifications to the original Cancer Transition Survey were also made through an iterative review process involving subject matter experts including the ITOC clinical leads (Dr. Murali Rajaraman and Dr. Syed Ali Imran), Dr. Robin Urquhart, Dr. Helena Piccinini-Vallis, and Dr. Annie Sawka from Princess Margaret Hospital. Items were again reviewed individually to improve question clarity, minimize risk of confusion and improve face validity for the DTC survivor population.

Most modifications to the survey consisted of specifying instructions and tailoring item responses to be more specific to DTC survivors. This included changing any mention of “cancer” to “thyroid cancer”, to avoid misunderstanding for survivors with multiple cancer diagnoses. Examples were also changed, such as in item 11 where “prostate cancer that has spread to the bones” was changed to “thyroid cancer that has spread to lymph nodes or lungs”. Items regarding cancer treatments were also changed for clarity, for example, streamlining options within item 16 which previously contained the potentially confusing “Hormone therapy”. Finally, items were changed to avoid capturing unrelated concepts, for example where the option of “Hormonal, menopause or fertility” was changed to “menstrual concerns or fertility concerns” to prevent confusion with thyroid

hormone replacement concerns and to make the option more specific to known long-term effects in DTC survivors. Five additional items were also created, bringing the total sum of items on the Modified Cancer Transition Survey up to 88. These additional items address thyroid hormone replacement concerns, and these data were intentionally not included for the current thesis work.

#### **4.4 Study Variables**

Demographic variables extracted were based upon those previously reported in publications based upon the national dataset of the CPAC Transitions Study (25) and the Nova Scotian cohort (85). A full list of all variables extracted, and their coding, is outlined in Table 5. Demographic variables included age group, gender, education, marital status, population size of residence, household income, employment status, number of individuals within a household, number of children (<18 years old) and immigration status. Disease-related variables extracted are also based upon these prior publications and include self-rated overall QoL, self-rated physical and emotional health, number of chronic conditions, diagnosis year, presence of metastases, type of treatment, and additional cancer diagnoses. All demographic and disease related variables are categorical variables, except for the gender variable where an open-ended “Other” option is present.

Table 5 List of Variables with Corresponding Survey Item Number and Categorization

<b>Variable</b>	<b>Survey Question</b>	<b>Variable Categorization</b>
Age	(3) How old are you?	1= "Under 18", 2= "18 to 24", 3= "25 to 34", 4= "35 to 44", 5= "45 to 54", 6= "55 to 64", 7= "65 to 74", 8= "75 to 84", 9= "85 or over", 10= "Prefer not to answer"
Gender	(2) Are you...?	1= "Male", 2= "Female", 3= "Other" <sup>1</sup> , 4= "Prefer not to answer"
Education	(76) What is your highest level of education?	1= "Grade school or less", 2= "Some high school", 3= "High school diploma or certificate", 4= "Some college or technical school/ CEGEP", 5= "College or technical school/ CEGEP", 6= "Some university", 7= "University undergraduate degree (Bachelor's)", 8= "University graduate degree (Master's or PhD)", 9= "Prefer to not answer"
Marital Status	(4) Are you currently...?	1= "Single (never married)", 2= "Married", 3= "Partnered (living with someone)", 4= "Separated", 5= "Divorced", 6= "Widowed", 7= "Prefer not to answer"
Population Size of Residence	(78) Which of the following best describes where you currently live?	1= "On an acreage, ranch or farm", 2= "In a town (less than 2,000 people)", 3= "In a town (2,000 and 10,000 people)", 4= "In a small city (10,000 and 50,000 people)", 5= "In a large city (more than 50,000 people)"

Variable	Survey Question	Variable Categorization
Yearly Household Income	(80) What is your total annual household income <u>before taxes</u> ? If you are a student and your healthcare needs are financially supported by your parents, please indicate your parents' total annual household income before taxes	1= "Less than \$25,000", 2= "\$25,000 to less than \$50,000", 3= "\$50,000 to less than \$75,000", 4= "\$75,000 to less than \$125,000", 5= "\$125,000 or more", 6= "Prefer not to answer"
Employment Status	(79) Which <u>ONE</u> of the following best describes your current employment situation?	1= "Working full time", 2= "Working part-time", 3= "On vacation or paid leave", 4= "On paid sick leave/ disability due to cancer", 5= "On paid sick leave/ disability due to other reason", 6= "I am a homemaker/ stay-at-home parent", 7= "I am a full-time student", 8= "I am retired", 9= "I am currently unemployed", 10= "Prefer not to answer"
Number of Individuals Within Household	(5) Including yourself, how many people live in your household?	1= "I live alone", 2= "2", 3= "3", 4= "4", 5= "5" or more
Number of Children Under 18 years of Age	(6) How many children under 18 years old do you have?	1= "No children under 18 years old", 2= "1 child", 3= "2 children", 4= "3 or more children", 5= "Prefer not to answer"
Immigration Status	(73) Were you born in Canada?	1= "Yes", 2= "No", 3= "Prefer not to answer"
<b>Disease-Related Variables</b>		
Self-Rated quality of Life	(8) How would you describe your overall quality of life today?	1= "Very good", 2= "Good", 3= "Fair", 4= "Poor", 5= "Very poor"
Self-Rated Physical Health	(9) In general, would you say your... physical health is...	1= "Very good", 2= "Good", 3= "Fair", 4= "Poor", 5= "Very poor"

Variable	Survey Question	Variable Categorization
Self-Rated Emotional Health	(9) In general, would you say your... emotional health is...	1= "Very good", 2= "Good", 3= "Fair", 4= "Poor", 5= "Very poor"
Number of Chronic Conditions	(10) Did you have any of the following chronic conditions <u>before</u> you were diagnosed with cancer? If you've been diagnosed with more than one type of cancer, please think about the chronic conditions you had prior to your most recent cancer diagnosis.	1= No chronic conditions, 2= One chronic condition selected, 3= Two chronic conditions selected, 4= Three or more chronic conditions selected
Diagnosis Year	(14) In what year were you diagnosed with cancer? Please remember to focus on your diagnosis of thyroid cancer	1= "Prior to 2010", 2= "2010", 3= "2011", 4= "2012", 5= "2013", 6= "2014", 7= "2015", 8= "2016", 9= "2017", 10= "2018", 11= "2019", 12= "2020"
Presence of Metastatic Disease	(15) Was this cancer diagnosed as metastatic, i.e., had the cancer spread to different parts of your body? Example: thyroid cancer that has spread to lymph nodes or lungs	1= "Yes, it was diagnosed as metastatic", 2= "No, it wasn't diagnosed as metastatic, but it spread afterwards", 3= "No, it wasn't diagnosed as metastatic, and it did not spread" 4= "Unsure"
Additional Cancer Diagnoses	(12) Have you ever been diagnosed with <u>more than one type of cancer</u> ? (for example, you have had breast cancer first and then thyroid cancer?)	1= "Yes", 2= "No", 3= "Unsure"

Variable	Survey Question	Variable Categorization
<b>Treatment Related Variables</b>		
Surgical Treatment	(15) What type(s) of cancer treatment did you receive for thyroid cancer, if any? Please X all the boxes that apply to you	1= If respondents selected "Surgery" option, 2= If respondents did not select "Surgery" option
RAI Treatment		1= If respondents selected "Radioactive iodine (I-131) therapy" option, 2= If respondents did not select "Radioactive iodine (I-131) therapy" option
Thyroid Hormone Replacement		1= If respondents selected "Thyroid hormone replacement therapy" option, 2= If respondents did not select "Thyroid hormone replacement therapy" option
Radiation Therapy		1= If respondents selected "Radiation therapy (external beam radiation) option, 2= If respondents did not select "Radiation therapy (external beam radiation)" option
<b>Physical Needs</b>		
Presence of need <sup>2</sup>	(34) How much was this a concern for you?	1= Recorded as Yes if respondents select "Big", "Moderate" or "Small", 2= Recorded as No if respondents select "Not a concern"
Degree of Concern <sup>2</sup>		1= Recorded as Severe if respondents select "Big", 2= Recorded as Moderate if respondents select "Moderate", 3= Recorded as Mild if respondents select "Small"
Difficulty Obtaining Help <sup>2,3</sup>	(36) How easy was it to get help for this concern?	1= Recorded as Yes if respondents select "Hard", "Very hard", or "Didn't get help", 2= Recorded as No if respondents select "Very easy" or "Easy"
Unmet Need <sup>2</sup>		1= Recorded as Yes if respondents select "Didn't get help", = Recorded as No if respondents select "Very easy" or "Easy", "Hard" or "Very hard"
<b>Emotional Needs</b>		
Presence of need <sup>2</sup>	(44) How much was this a concern for you?	1= Recorded as Yes if respondents select "Big", "Moderate" or "Small", 2= Recorded as No if respondents select "Not a concern"

<b>Variable</b>	<b>Survey Question</b>	<b>Variable Categorization</b>
Degree of Concern <sup>2</sup>		1= Recorded as Severe if respondents select "Big", 2= Recorded as Moderate if respondents select "Moderate", 3= Recorded as Mild if respondents select "Small"
Difficulty Obtaining Help <sup>2,3</sup>	(46) How easy was it to get help for this concern?	1= Recorded as Yes if respondents select "Hard", "Very hard", or "Didn't get help", 2= Recorded as No if respondents select "Very easy" or "Easy"
Unmet Need <sup>2</sup>		1= Recorded as Yes if respondents select "Didn't get help", = Recorded as No if respondents select "Very easy" or "Easy", "Hard" or "Very hard"
<b>Practical Needs</b>		
Presence of need <sup>2</sup>	(54) How much was this a concern for you?	1= Recorded as Yes if respondents select "Big", "Moderate" or "Small", 2= Recorded as No if respondents select "Not a concern"
Degree of Concern <sup>2</sup>		1= Recorded as Severe if respondents select "Big", 2= Recorded as Moderate if respondents select "Moderate", 3= Recorded as Mild if respondents select "Small"
Difficulty Obtaining Help <sup>2,3</sup>	(56) How easy was it to get help for this concern?	1= Recorded as Yes if respondents select "Hard", "Very hard", or "Didn't get help", 2= Recorded as No if respondents select "Very easy" or "Easy"
Unmet Need <sup>2</sup>		1= Recorded as Yes if respondents select "Didn't get help", = Recorded as No if respondents select "Very easy" or "Easy", "Hard" or "Very hard"
<b>Informational Needs</b>		
Unmet Need <sup>2</sup>	(31) In general, how much do you agree or disagree with the following statements about the information you were given after completing thyroid cancer treatment?	1= Recorded as Yes if respondents select "Somewhat disagree" or "Strongly disagree", 2= Recorded as No if respondents select "Strongly agree", "Somewhat agree", "Neither agree nor disagree" or "Not applicable"

1. For “Other” the full responses give the option to specify. These open text responses were recorded separately.
2. Variables were calculated separately for each need specified to be assessed within a particular domain
3. Respondents must have answered “Yes” to the previous question asking “Did you seek help for this concern”
4. Respondents are asked to “...disregard any challenges due to COVID-19 pandemic related restrictions” for this domain (Appendix A)

Physical, emotional and practical needs were evaluated as previously published (25) and using items 34-36, 44-46 and 54-56, respectively. Variables of interest for these domains are (i) the presence of a need within an individual domain, (ii) the degree of concern, (iii) if a respondent sought help for a concern, (iv) if a respondent had difficulty finding help for that concern and (v) if a respondent reported an unmet need. The presence of a need in each of the domains is defined by a respondent selecting “Big”, “Moderate” or “Small” in response to “How was this a concern for you?”. The degree of concern is categorized as either (i) severe (“Big”), (ii) moderate (“Moderate”) or (iii) mild (“Small”). Difficulty obtaining help is a binary variable (yes/no), with responses of “Hard”, “Very Hard” or “Didn’t get help” to “How easy was it to get help for this concern?” indicating a positive response. The presence of an unmet need is defined as a respondent answering “Didn’t get any help” regardless of if they indicated that they had sought help for that concern or not.

Unmet informational needs were evaluated through responses to item 31, which asks, “In general, how much do you agree or disagree with the following statements about the information you were given after completing thyroid cancer

treatment?”. All variables in this domain were binary (yes/no) variables, and include whether information was available, if the information was useful, if it was in a respondent’s preferred language and if they were given information about signs of cancer recurrence, side effects of treatment and community resources. Due to the differences in formatting, responses of “Somewhat disagree” and “Strongly disagree” are categorized as endorsing an unmet need for these variables.

## **4.5 Analysis**

### *Descriptive Analyses*

For all analyses, only valid responses and non-missing data were utilized for each questionnaire item assessed. The frequency and percentage of missing and/or non-valid responses for each portion of the analyses was recorded. Descriptive analysis using frequencies and percentages for both demographic variables and disease-related variables was performed separately for (i) the sample of DTC survivors and (ii) the comparative sample of breast cancer, colorectal cancer, prostate cancer, melanoma, hematologic malignancies and other (i.e., AYA) cancer survivors.

### Analyses for objective 1

*Objective 1: To describe the self-reported physical, emotional, practical and informational needs of low-risk DTC survivors in Nova Scotia during the transition period to primary care.*

This portion of the analysis only used self-reported data from DTC survivors. The frequency and percentage of respondents with the presence of a need was calculated for each individual question within the physical, emotional and practical domains. Corresponding frequencies and percentages were also calculated for whether the degree of concern was (1) mild (2) moderate or (3) severe, with the denominator being the number of respondents who reported they had either a severe, moderate or mild concern. Similar calculations were performed for the frequency and percentage of respondents who sought help for a concern, with the number of respondents who answered the question “Did you seek help for this concern?” for a corresponding need serving as the denominator. Percentages for whether a respondent had difficulty finding help and if a need was unmet were calculated using the number of responses to “How easy was it to get help for this concern?” as the denominator. The frequencies for the presence of individual needs per domain were also cross tabulated with the corresponding degree of concern and frequency of difficulty obtaining help for a concern to assess for any patterns. Frequencies and percentages for informational needs were calculated using the number of respondents who answered individual questions as the denominator.

### Analyses for objective 2

*Objective 2: To compare the reported physical, emotional, practical and informational needs of DTC survivors during the transition period against breast*

*cancer, colorectal cancer, prostate cancer, melanoma and hematologic cancer survivors.*

This portion of the analysis used data from both DTC survivors and from the 2016 Nova Scotia adult and AYA cohort of the CPAC Transitions survey.

Frequencies and proportions were calculated separately for each individual need within the physical, emotional and practical needs domains using the number of respondents who (i) reported the presence of a need and (ii) that this need was unmet. Due to formatting differences, only the frequency and proportion of unmet needs were calculated for each individual need within the informational need domain. All calculations were done separately for the DTC survivors' group and the comparative group consisting of all adults and AYA cancer survivors in the Nova Scotia cohort from the 2016 Cancer Transition Study. The proportions of the (i) prevalence of each individual need and the (ii) prevalence of an individual need being unmet were compared between the DTC survivors and the 2016 comparative sample using Pearson  $\chi^2$  tests. The null hypothesis for each of these analyses will follow equation (1) below, or that the proportion of needs/unmet needs in the DTC sample ( $p_1$ ) will be equal to those of other cancer survivors ( $p_2$ ). Sample tables that will be used for calculations related to Objective 2 can be seen in Table 10.

(1) 
$$H_0: p_1 = p_2$$

### *Power Calculation*

For this study, the sample size needed for Objective 1 was dependent upon our response rates. For Objective 2, the minimum sample size required to detect an effect size of 20% assuming an  $\alpha$  of 0.05 and a power (1- $\beta$ ) of 80% is 97. This was calculated by assuming a 60% prevalence of an individual need within the comparative sample and a 40% prevalence within the DTC sample. A total of 375 survey packages were mailed to the DTC survivor group. Using a conservative estimated response rate of 30%, it was estimated that we would receive 112 completed surveys; therefore, the number of potential participants identified would result in enough respondents to adequately power this study.

### *Sensitivity Analyses*

To assess for any potential selection bias, the age and gender of all 375 individuals who were sent a research package were tabulated according to the variables “age” and “gender” in Table 5, and then compared to the data from the survey respondents. Additionally, it was predetermined that any supportive care needs in the DTC sample, which were significantly different compared to the comparative sample, would be cross tabulated by diagnosis year to assess for any gross differences related to post-treatment times. The lengths of time after diagnosis chosen were within the last 5 years (diagnosed between 2020 and

2016 inclusive), between 5 to 10 years (diagnosed between 2015 and 2010 inclusive) and greater than 10 years (diagnosed before 2010).

## CHAPTER 6 RESULTS

### i. Response Rate

A total of 375 survey packages were sent out for completion. During the six-week study period, 10 individuals contacted the team to withdraw from the study, and were therefore excluded. 51 responses were collected from the online REDcap system, which after excluding duplicates and responses for which no answers were saved, left 44 online surveys included for analysis. A total of 161 written survey responses were also mailed back during the study period. The total number of collected surveys included in the analysis was 205, representing a 54.6% response rate. The Nova Scotian cohort of the CPAC data totaled 1557 respondents (44.6% response rate) (85).

### ii. Demographics

Missing values are recorded alongside other sociodemographic information from the DTC sample and CPAC sample in Table 6. Missing values were not included in calculating response frequencies. The most common age category reported for the DTC sample was between 55 to 64 years old (28.2%) and between 65 to 74 (28.2%) years old (Figure 2). The most common age category range for the CPAC sample was 65 to 74 (38.7%) years old. Most respondents in the DTC sample (81.2%) and CPAC sample (51.9%) identified as female (Figure 3). The highest level of education attained was also collected and is shown in Figure 4. Most respondents were married (68.5% vs 69.6%, respectively) and lived in two

person households (57.1% vs. 66.2%, respectively) with no children (86.1 vs 91.3%, respectively). The most common yearly income reported in the DTC sample was between \$75,000 to \$125,000 (25.8%) in comparison to \$25,000 to \$50,000 in the NS CPAC sample (27.6%) (Figure 5). Most respondents in both the DTC sample and CPAC sample reported being born in Canada (91.5% vs 91.6%, respectively), being retired, and living in an urban center with more than 50,000 people (35.7% vs 27.3%, respectively) (Figure 6).

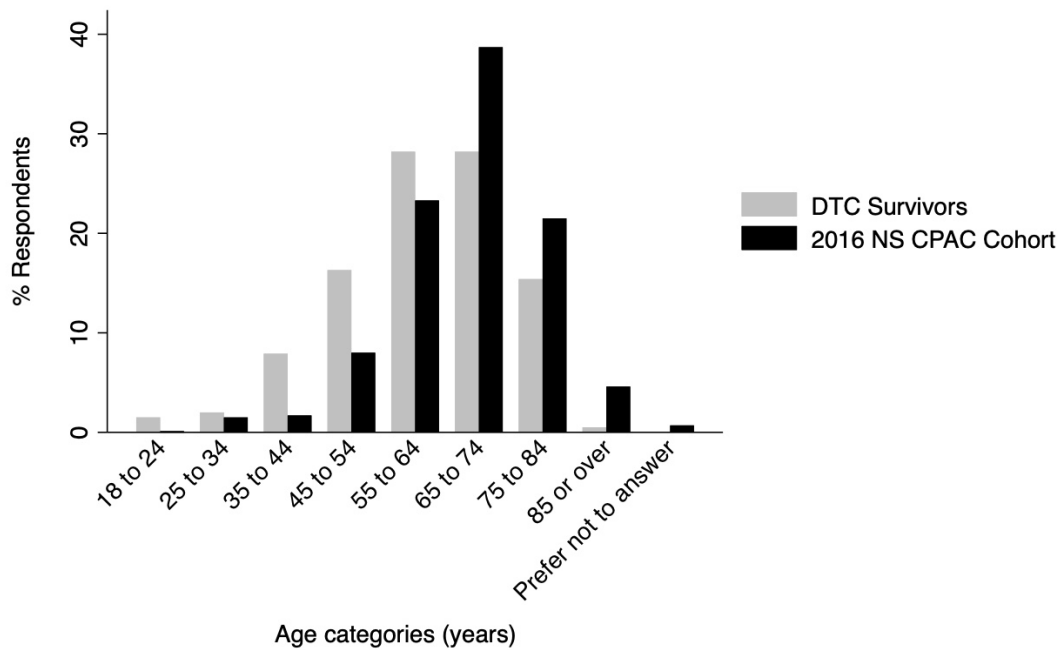


Figure 2 Age Distribution of DTC Survivor Sample ( $n=202$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1514$ )

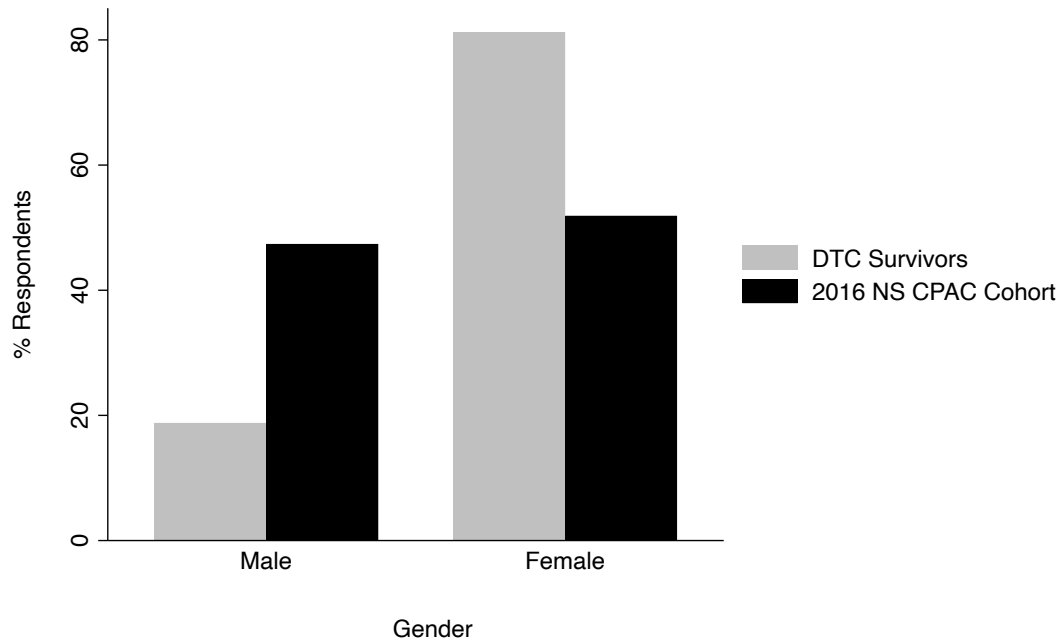


Figure 3 Gender Distribution of DTC Survivor Sample ( $n=202$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1514$ )

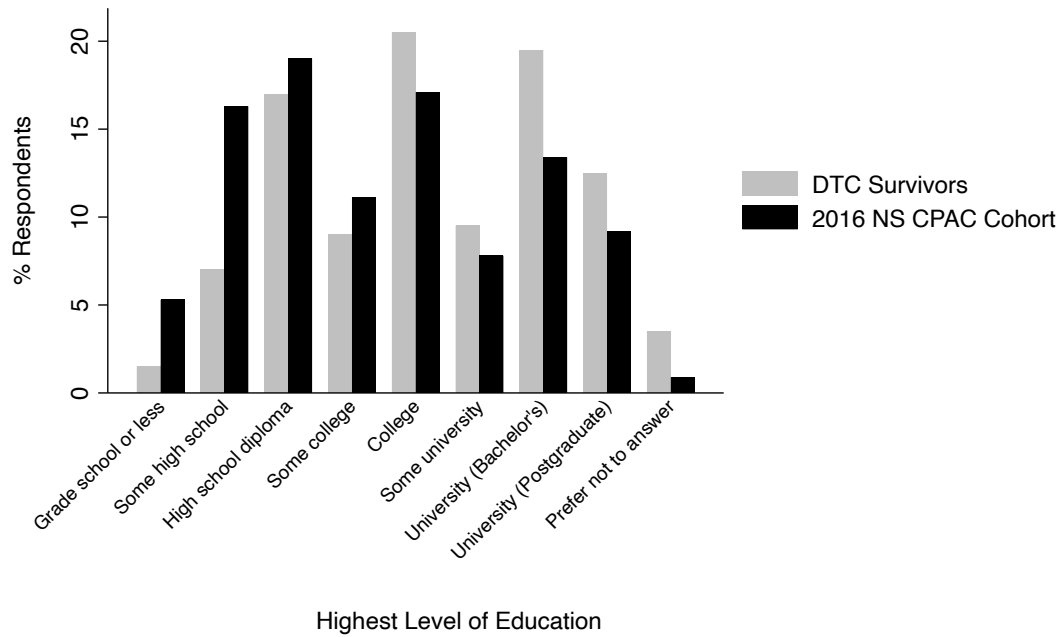


Figure 4 Highest Level of Education Attained by DTC Survivor Sample ( $n=200$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1461$ )

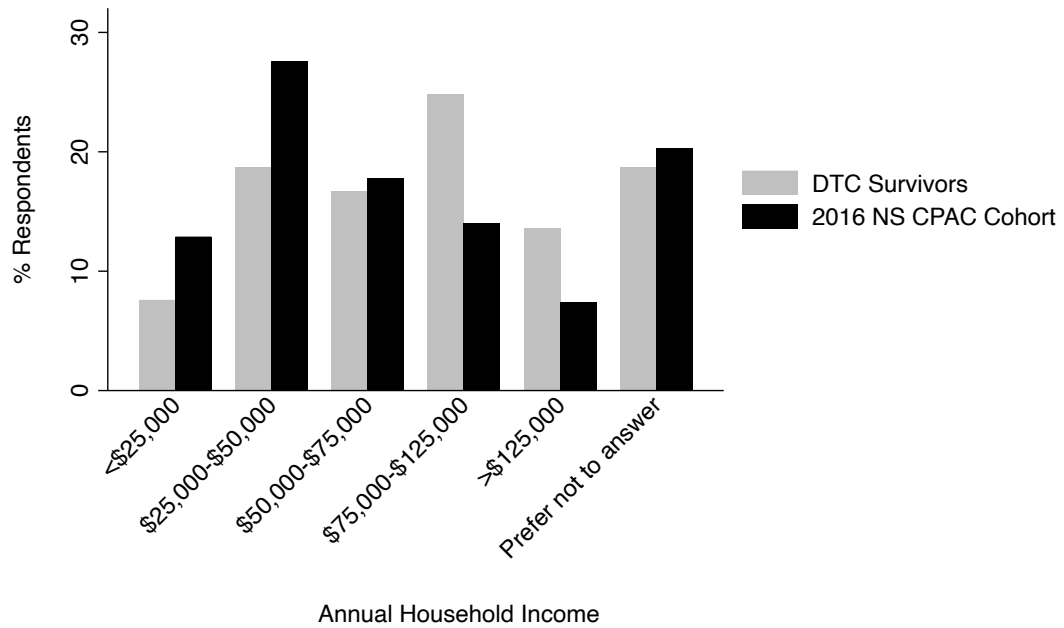


Figure 5 Annual Household Income Distribution of DTC Survivor Sample ( $n=198$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1445$ )

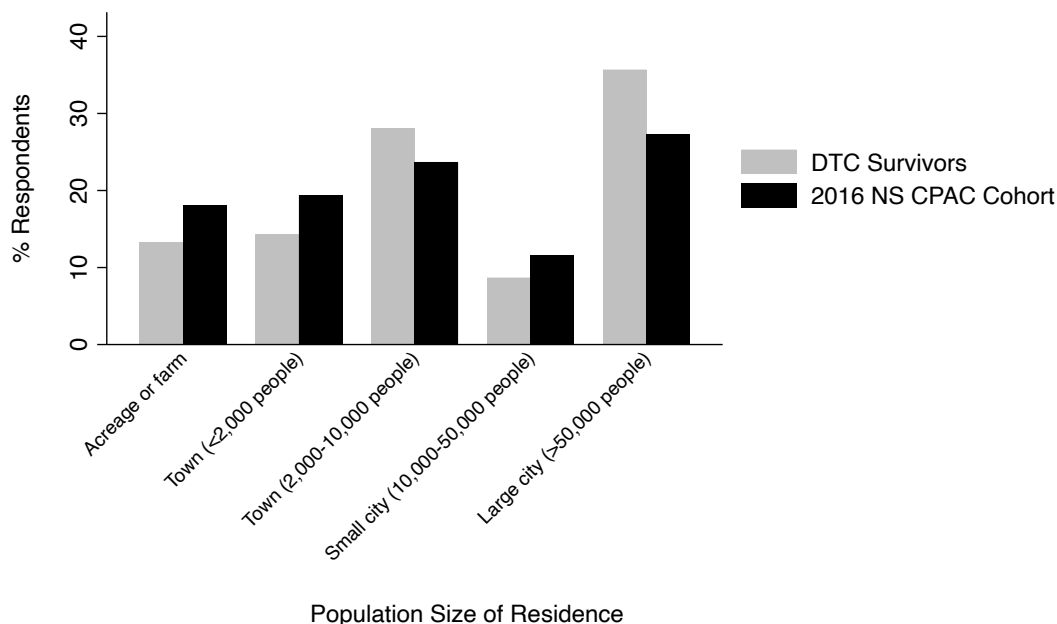


Figure 6 Population Size of Residence Distribution of DTC Survivor Sample ( $n=196$ ) and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors ( $n=1454$ )

Table 6 Descriptive Analysis of Demographic Variables in DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors<sup>1</sup>

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency (%)	Number	Frequency (%)
<b>Age</b>				
Under 18	0	0	0	0
18 to 24	3	1.5	1	0.1
25 to 34	4	2.0	22	1.5
35 to 44	16	7.9	26	1.7
45 to 54	33	16.3	121	8.0
55 to 64	57	28.2	352	23.3
65 to 74	57	28.2	586	38.7
75 to 84	31	15.4	325	21.5
85 or over	1	0.5	70	4.6
Prefer not to answer	0	0.0	11	0.7
Missing <sup>2</sup>	3	1.5	0	0.0

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency (%)	Number	Frequency (%)
<b>Gender</b>				
Male	38	18.8	718	47.4
Female	164	81.2	785	51.9
Other	0	0.0	2	0.1
Prefer not to answer	0	0.0	9	0.6
Missing <sup>2</sup>	3	1.5	0	0.0
<b>Education</b>				
Grade school or less	3	1.5	77	5.3
Some high school	14	7.0	238	16.3
High school diploma or certificate	34	17.0	277	19.0
Some college or technical school/ CEGEP	18	9.0	162	11.1
College or technical school/ CEGEP	41	20.5	250	17.1
Some university	19	9.5	114	7.8
University undergraduate degree (Bachelor's)	39	19.5	195	13.4
University postgraduate degree (Master's or PhD)	25	12.5	135	9.2
Prefer Not to Answer	7	3.5	13	0.9
Missing <sup>2</sup>	5	2.4	53	3.5
<b>Marital Status</b>				
Single (never married)	14	6.9	83	5.5
Married	139	68.5	1053	69.6
Partnered (living with someone)	12	5.9	87	5.8
Separated	3	1.5	29	1.9
Divorced	11	5.4	77	5.1
Widowed	22	10.8	169	11.2
Prefer not to answer	2	1.0	16	1.1
Missing <sup>2</sup>	2	1.0	0	0.0
<b>Yearly Household Income</b>				
Less than \$25,000	15	7.6	187	12.9

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency (%)	Number	Frequency (%)
\$25,000 to less than \$50,000	37	18.7	399	27.6
\$50,000 to less than \$75,000	33	16.7	257	17.8
\$75,000 to less than \$125,000	49	24.8	202	14.0
\$125,000 or more	27	13.6	107	7.4
Prefer not to answer	37	18.7	293	20.3
Missing <sup>2</sup>	7	3.4	69	4.6
<b>Number of Individuals in Household</b>				
I live alone	36	17.7	262	17.4
2	116	57.1	995	66.1
3	25	12.3	152	10.1
4	22	10.8	57	3.8
5 or more	4	2.0	39	2.6
Missing <sup>2</sup>	2	1.0	9	0.6
<b>Number of Children Under 18 Years of Age</b>				
No children under 18 years of age	173	86.1	1347	91.3
1 child	16	8.0	67	4.5
2 children	9	4.5	39	2.6
3 or more children	3	1.5	16	1.1
Prefer not to answer	0	0.0	7	0.5
Missing <sup>2</sup>	4	2.0	38	2.5
<b>Population Size of Residence</b>				
On an acreage, ranch or farm	26	13.3	263	18.1
In a town (less than 2,000 people)	28	14.3	282	19.4
In a town (2,000 and 10,000 people)	55	28.1	344	23.7
In a small city (10,000 and 50,000 people)	17	8.7	168	11.6
In a large city (more than 50,000 people)	70	35.7	397	27.3
Missing <sup>2</sup>	9	4.4	60	4.0
<b>Employment Status</b>				
Working full-time	57	29.4	246	17.0

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency (%)	Number	Frequency (%)
Working part-time	15	7.7	107	7.4
On vacation or paid leave	1	0.5	1	0.1
On paid sick leave/ disability leave due to cancer	0	0.0	19	1.3
On paid sick leave/ disability leave due to other reason	5	2.6	22	1.5
I am a homemaker/ stay-at-home parent	4	2.1	36	2.5
I am a full-time student	1	0.5	4	0.3
I am retired	103	53.1	968	66.2
I am currently unemployed	5	2.6	34	2.3
Prefer not to answer	3	1.6	16	1.1
Missing <sup>2</sup>	11	5.4	61	4.0
<b>Immigration Status</b>				
Was born in Canada	184	91.6	1347	91.6
Was not born in Canada	17	8.5	119	8.1
Prefer not to answer	0	0.0	4	0.3
Missing <sup>2</sup>	4	2.0	44	2.9

1. The comparative sample comprised of the adult and AYA cohorts from the 2016 CPAC Cancer Transition Study from Nova Scotia
2. The denominator in calculating the frequency of missing values for variables from the DTC and comparative sample were 205 and 1514 respectively, representing the total number of surveys collected

iii. Disease and Treatment Related Variables in DTC Sample

The prevalence and frequencies for all disease related variables in the DTC sample and comparative sample is listed in Table 7. Most respondents rated their self-reported QoL (51.0% vs 43.3%), physical health (60.1% vs 49.3%) and emotional health (47.8% vs 46.2%) as “Good” in both the DTC sample and comparative sample, respectively. Most respondents in the DTC sample had at

least one chronic condition (57.6%). Most respondents in both the DTC and comparative sample reported not having any additional cancer diagnoses (81.0% vs 85.2%) and that their primary cancer did not metastasize (81.8% vs 80.8%). For diagnosis year, most respondents in the DTC sample reported having been diagnosed prior to 2010 (38.7%), whereas most respondents in the comparative group reported being diagnosed in 2014 (22.3%).

Table 7 Descriptive Analysis of Disease Related Variables in DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors<sup>1</sup>

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency <sup>2</sup> (%)	Number	Frequency (%)
<b>Self-Reported Quality of Life</b>				
Very good	69	33.8	625	41.5
Good	104	51.0	653	43.3
Fair	26	12.8	211	14.0
Poor	3	1.5	15	1.0
Very Poor	2	1.0	3	0.2
Missing <sup>3</sup>	1	0.5	7	0.5
<b>Self-Reported Physical Health</b>				
Very good	33	16.3	400	26.7
Good	122	60.1	747	49.3

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency <sup>2</sup> (%)	Number	Frequency (%)
Fair	41	20.2	314	20.9
Poor	6	3.0	35	2.3
Very Poor	1	0.5	5	0.3
Missing <sup>3</sup>	2	1.0	13	0.9
<b>Self-Reported Emotional Health</b>				
Very good	50	25.4	503	35.0
Good	97	49.2	663	46.2
Fair	39	19.8	222	15.5
Poor	5	2.5	40	2.8
Very Poor	6	3.1	8	0.6
Missing <sup>3</sup>	8	3.9	78	5.2
<b>Number of Chronic Conditions<sup>4</sup></b>				
None	87	42.4		
1 chronic condition	66	32.2		
2 chronic conditions	31	15.1		
3 or more chronic conditions	21	10.2		
Missing <sup>3</sup>	0	0.0		

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency <sup>2</sup> (%)	Number	Frequency (%)
<b>Diagnosis Year</b>				
Prior to 2010	75	38.7	50	3.5
2010	14	7.2	11	0.8
2011	10	5.2	46	3.2
2012	18	9.3	311	21.6
2013	16	8.3	682	47.3
2014	9	4.6	322	22.3
2015	8	4.1	46	3.2
2016	8	4.1		
2017	12	6.2		
2018	8	4.1		
2019	11	5.7		
2020	5	2.6		
Missing <sup>3</sup>	11	5.4	46	3.0
<b>Presence of Metastatic Disease</b>				
Yes, it was diagnosed as metastatic	13	6.6	75	5.3
No, it wasn't diagnosed as metastatic, but it spread afterwards	5	2.5	54	3.8
No, it wasn't diagnosed as metastatic, and it did not spread	162	81.8	1155	80.8

Variable	DTC Sample		Comparative Sample <sup>1</sup>	
	Number	Frequency <sup>2</sup> (%)	Number	Frequency (%)
Unsure	18	9.1	145	10.2
Missing <sup>3</sup>	7	3.4	85	5.6
<b>Additional Cancer Diagnoses</b>				
Yes	35	17.1	206	13.9
No	166	81.0	1258	85.1
Unsure	4	2.0	14	1.0
Missing <sup>3</sup>	0	0.0	36	2.4

1. The comparative sample comprised of the adult and AYA cohorts from the 2016 CPAC Cancer Transition Study from Nova Scotia.
2. The denominator in calculating the frequency of responses was the total number of responses per item, excluding missing values.
3. The denominator in calculating the frequency of missing values for variables from the DTC and comparative sample were 205 and 1514 respectively, representing the total number of surveys collected.
4. Due to coding differences, we were unable to calculate the prevalence and frequencies for the chronic condition variable in the comparative sample.

Prevalence and frequencies for all treatment related variables in the DTC sample are listed in Table 8. Of the 202 survey respondents who responded to this item, 174 (86.1%) reported having received surgery for their thyroid cancer, 140 (69.3%) reported receiving RAI therapy, two reported receiving radiation therapy (1.0%) and 128 respondents reported receiving thyroid hormone replacement (63.4%).

Table 8 Descriptive Analysis of Treatment Related Variables in DTC Survivor Sample

Variable	DTC Sample	
	Number	Frequency (%) <sup>1</sup>
Surgery	174	86.1
Radioactive iodine (I-131) therapy	140	69.3
Thyroid hormone replacement therapy	128	63.4
Radiation therapy (external-beam radiation therapy)	2	1.0
Missing <sup>2</sup>	3	1.5

1. The denominator in calculating the frequency of responses was 202 which the total number of responses to item 16, excluding missing values.
2. The denominator in calculating the frequency of missing values was 205, representing the total number of surveys collected.

iv. Prevalence of Supportive Care Needs in DTC Sample

The prevalence, frequency and reported severity of all supportive care needs in the physical, emotional and practical domains are all listed in Table 9, 10 and 11, respectively. The three most prevalent needs in the physical domain were “fatigue, tiredness” (81.3%), “changes to concentration, memory” (43.2%) and “nerve problems” (33.5%). Most respondents who reported “fatigue, tiredness” as a concern reported that it was “severe” (40.4%). The majority of survey respondents who reported changes to “concentration, memory” rated it as “moderate” (37.7%), whereas most respondents who reported “nerve problems” as a concern reported it as “mild” (37.9%).

Table 9 Descriptive Analysis of Needs Within the Physical Domain for DTC Survivors

Supportive Care Need	No. of responses for need item <sup>1</sup>	Missing Data (%) for need item <sup>2</sup>	Need was present, <i>n</i> (%) <sup>3</sup>	Severe Need, <i>n</i> (%) <sup>4</sup>	Moderate Need, <i>n</i> (%)	Mild Need, <i>n</i> (%)
Swelling of arms or legs	197	3.9	32 (16.2)	8 (25.0)	13 (40.6)	11 (34.4)
Fatigue, tiredness	198	3.4	161 (81.3)	65 (40.4)	53 (32.9)	43 (26.7)
Menstrual concerns or fertility concerns	193	5.9	31 (16.1)	12 (38.7)	13 (41.9)	6 (19.4)
Chronic pain or long-term pain	197	3.9	58 (29.4)	23 (39.7)	25 (43.1)	10 (17.2)
Bladder and/or urinary problems (i.e., incontinence)	200	2.4	40 (20.0)	10 (25.0)	15 (37.5)	15 (37.5)
Gastrointestinal problems (i.e., constipation, diarrhea)	197	3.9	58 (29.4)	19 (32.8)	24 (41.4)	15 (25.9)
Nerve problems (numbness or tingling in the hands/ feet)	197	3.9	66 (33.5)	17 (25.8)	24 (36.4)	25 (37.9)
Changes to concentration, memory	197	3.9	85 (43.2)	28 (32.9)	32 (37.7)	25 (29.4)
Changes in sexual activity or function	198	3.4	54 (27.3)	12 (22.2)	27 (50.0)	15 (27.8)

1. Needs items are defined as item 34 for the physical domains.
2. The denominator in calculating the frequency of missing values was 205, representing the total number of surveys collected.
3. The denominator in calculating the frequency of responses was the total number of responses for the need item, excluding missing values.
4. The denominator in calculating the frequency of need severity was the total number of responses for whether the need was present, excluding missing values.

The three most prevalent needs in the emotional domain (Table 10) were “anxiety, stress, worry about cancer returning” (69.5%), “depression, sadness, loss of interest in everyday things” (46.3%) and “changes in body image” (42.4%). Most survey respondents who reported “anxiety, stress, worry about cancer returning” (37.4%) and “changes to body image” (40.5%) rated it as a “mild” concern. Most respondents who reported “depression, sadness, loss of interest in everyday things” rated it as a “moderate” concern (38.7%).

Table 10 Descriptive Analysis of Needs Within the Emotional Domain for DTC Survivors

<b>Supportive Care Need</b>	<b>No. of responses for need item<sup>1</sup></b>	<b>Missing Data (%) for need item<sup>2</sup></b>	<b>Need was present, <i>n</i> (%)<sup>2</sup></b>	<b>Severe Need, <i>n</i> (%)<sup>4</sup></b>	<b>Moderate Need, <i>n</i> (%)</b>	<b>Mild Need, <i>n</i> (%)</b>
Depression, sadness, loss of interest in everyday things	201	2.0	93 (46.3)	28 (30.1)	36 (38.7)	29 (31.2)
Anxiety, stress, worry about cancer returning	200	2.4	139 (69.5)	42 (21.0)	45 (32.4)	52 (37.4)
Changes in relationships with family, partners	200	2.4	50 (25.0)	8 (16.0)	19 (38.0)	23 (46.0)
Changes in relationships with friends or coworkers	200	2.4	42 (21.0)	8 (19.1)	14 (33.3)	20 (47.6)

<b>Supportive Care Need</b>	<b>No. of responses for need item<sup>1</sup></b>	<b>Missing Data (%) for need item<sup>2</sup></b>	<b>Need was present, <i>n</i> (%)<sup>2</sup></b>	<b>Severe Need, <i>n</i> (%)<sup>4</sup></b>	<b>Moderate Need, <i>n</i> (%)</b>	<b>Mild Need, <i>n</i> (%)</b>
Changes in body image (i.e. confidence in appearance, etc.)	198	3.4	84 (42.4)	25 (29.8)	25 (29.8)	34 (40.5)
Changes in sexual intimacy	199	2.9	53 (26.6)	17 (32.1)	13 (24.5)	23 (43.4)

1. Needs items are defined as item 44 for the emotional domain.
2. The denominator in calculating the frequency of missing values was 205, representing the total number of surveys collected.
3. The denominator in calculating the frequency of responses was the total number of responses for the need item, excluding missing values.
4. The denominator in calculating the frequency of need severity was the total number of responses for whether the need was present, excluding missing values.

The three most reported needs in the practical domain (Table 11) were “returning to (or future) work or school” (29.2%), “difficulty getting health or life insurance” (21.6%) and “paying healthcare bills” (20.6%). Of the respondents who reported “returning to work or school” as well as “paying healthcare bills” as concerns, most said that it was a “mild” concern (37.9% and 41.5%, respectively). Most respondents who reported “difficulty getting health or life insurance” said it was a “severe” concern (48.8%).

Table 11 Descriptive Analysis of Needs Within the Practical Domain for DTC Survivors

Supportive Care Need	No. of responses for need item <sup>1</sup>	Missing Data (%) for need item <sup>2</sup>	Need was present, <i>n</i> (%) <sup>3</sup>	Severe Need, <i>n</i> (%) <sup>4</sup>	Moderate Need, <i>n</i> (%)	Mild Need, <i>n</i> (%)
Returning to (or future) work or school	199	2.9	58 (29.2)	17 (29.3)	19 (32.8)	22 (37.9)
Getting to and from appointments	197	3.9	30 (15.3)	3 (10.0)	9 (30.0)	18 (60.0)
Taking care of children, elderly, or other family members	199	2.9	34 (17.1)	5 (14.7)	11 (32.4)	18 (52.9)
Difficulty getting health or life insurances	199	2.9	43 (21.6)	21 (48.8)	14 (32.6)	8 (18.6)
Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)	199	2.9	41 (20.6)	8 (19.5)	16 (39.0)	17 (41.5)

1. Needs items are defined as item 54 for the practical domain.
2. The denominator in calculating the frequency of missing values was 205, representing the total number of surveys collected.
3. The denominator in calculating the frequency of responses was the total number of responses for the need item, excluding missing values.
4. The denominator in calculating the frequency of need severity was the total number of responses for whether the need was present, excluding missing values.

For the prevalence and frequencies of the supportive care needs in the comparative sample that were calculated and used in this study in the physical, emotional and practical domains, refer to Tables 12, 13 and 14, respectively.

Table 12 Descriptive Analysis of Needs Within the Practical Domain for Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors

<b>Supportive Care Need</b>	<b>No. of responses for need item<sup>1</sup></b>	<b>Missing Data (%) for need item<sup>2</sup></b>	<b>Need was present <i>n</i> (%)<sup>3</sup></b>
Swelling of arms or legs	1374	9.2	289 (21.0)
Fatigue, tiredness	1400	7.5	900 (64.3)
Menstrual concerns or fertility concerns	1352	10.7	293 (21.7)
Chronic pain or long-term pain	1378	9.0	411 (29.8)
Bladder and/or urinary problems (i.e., incontinence)	1392	8.0	438 (31.5)
Gastrointestinal problems (i.e., constipation, diarrhea)	1386	8.5	464 (33.5)
Nerve problems (numbness or tingling in the hands/ feet)	1385	8.5	435 (31.4)
Changes to concentration, memory	1384	8.6	452 (32.7)
Changes in sexual activity or function	1403	7.3	591 (42.1)

1. Needs items are defined as item 34 for the physical domain.
2. The denominator in calculating the frequency of missing values was 1514, representing the total number of surveys collected in the comparative sample.
3. The denominator in calculating the frequency of responses was the total number of responses for the need item, excluding missing values.

Table 13 Descriptive Analysis of Needs Within the Emotional Domain for Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors

<b>Supportive Care Need</b>	<b>No. of responses for need item<sup>1</sup></b>	<b>Missing Data (%) for need item<sup>2</sup></b>	<b>Need was present, <i>n</i></b>
Depression, sadness, loss of interest in everyday things	1273	15.9	536 (42.1)
Anxiety, stress, worry about cancer returning	1280	15.5	822 (64.2)
Changes in relationships with family, partners	1425	5.9	412 (28.9)
Changes in relationships with friends or coworkers	1416	6.5	228 (16.1)
Changes in body image (i.e., confidence in appearance, etc.)	1412	6.7	516 (36.5)
Changes in sexual intimacy	1411	6.8	562 (39.8)

1. Needs items are defined as item 44 for the emotional domain.
2. The denominator in calculating the frequency of missing values was 1514, representing the total number of surveys collected in the comparative sample.

Table 14 Descriptive Analysis of Needs Within the Practical Domain for Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors

<b>Supportive Care Need</b>	<b>No. of responses for need item<sup>1</sup></b>	<b>Missing Data (%) for need item<sup>2</sup></b>	<b>Need was present, <i>n</i></b>
Returning to (or future) work or school	1387	8.4	264 (19.0)
Getting to and from appointments	1411	6.8	236 (16.7)

<b>Supportive Care Need</b>	<b>No. of responses for need item<sup>1</sup></b>	<b>Missing Data (%) for need item<sup>2</sup></b>	<b>Need was present, <i>n</i></b>
Taking care of children, elderly, or other family members	1393	8.0	153 (11.0)
Difficulty getting health or life insurances	1388	8.3	184 (13.3)
Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)	1405	7.2	265 (18.9)

1. Needs items are defined as item 54 for the practical domain.
2. The denominator in calculating the frequency of missing values was 1514, representing the total number of surveys collected in the comparative sample.

v. Difficulty Obtaining Help and Unmet Needs in DTC Sample

The prevalence and frequency of respondents seeking help, whether respondents had difficulty seeking help and if a need was unmet for all supportive care needs in the physical, emotional and practical domains are listed in Table 15, 16 and 17, respectively. The three items with the highest frequency of respondents reporting that they sought help for that concern in the physical domain were “fatigue, tiredness” (53.8%), “nerve problems” (47.8%) and “chronic pain or long-term pain” (46.8%). For those who reported “fatigue, tiredness” as a concern, 63.7% reported difficulty getting help. For those who reported “nerve problems” as a concern, 61.9% had difficulty obtaining help, as did 60.5% of respondents who reported “chronic pain or long-term pain” as a concern. The need with the highest frequency of difficulty in obtaining help for respondents who reported it as a concern was “changes to concentration, memory” at 76.1% of respondents. The three items with the highest reported frequency of unmet needs in the physical domain were “changes to sexual activity or function”

(52.2%), “changes to concentration, memory” (43.5%) and “fatigue, tiredness” (33.0%).

Table 15 Descriptive Analysis of Seeking Help and Unmet Needs Within the Physical Domain for DTC Survivors

Supportive Care Need	No. of responses for help item <sup>1</sup>	Missing Data (%) for help item <sup>2</sup>	Help was sought, <i>n</i> (%)	No. of responses for ease of help item <sup>3</sup>	Had difficulty getting help <i>n</i> , (%) <sup>4</sup>	Unmet Need <i>n</i> , (%) <sup>4</sup>
Swelling of arms or legs	63	5.4	17 (27.0)	25	15 (60.0)	7 (28.0)
Fatigue, tiredness	158	3.4	85 (53.8)	102	65 (63.7)	34 (33.0)
Menstrual concerns or fertility concerns	64	11.2	28 (31.3)	21	12 (57.1)	4 (19.1)
Chronic pain or long-term pain	79	7.8	37 (46.8)	43	26 (60.5)	8 (18.6)
Bladder and/or urinary problems (i.e., incontinence)	63	10.2	22 (34.9)	28	13 (46.4)	5 (17.9)
Gastrointestinal problems (i.e., constipation, diarrhea)	80	9.3	35 (43.8)	39	14 (35.9)	4 (10.3)
Nerve problems (numbness or tingling in the hands/ feet)	82	7.3	39 (47.6)	42	26 (61.9)	11 (26.2)
Changes to concentration, memory	100	7.8	34 (34.0)	46	35 (76.1)	20 (43.5)
Changes in sexual activity or function	78	9.8	18 (12.8)	23	16 (69.6)	12 (52.2)

1. The help item is defined as items 35 for the physical domain.
2. The denominator in calculating the frequency of missing values was 205, representing the total number of surveys collected in the DTC sample.
3. Ease of help item is defined as item 36 for the physical domain, and responses exclude those who answered “Not a concern” in item 34.

4. The denominator in calculating the frequency of responses was the total number of responses for the ease of help item, excluding missing values.

In the emotional domain (Table 16), the three items with the highest frequency of respondents seeking help for a concern were “depression, sadness, loss of interest in everyday things” (41.8%), “anxiety, stress, worry about cancer returning” (31.9%) and “changes in body image” (16.2%). Almost 51% of respondents who reported “depression, sadness, loss of interest in everyday things” reported that it was difficult to find help so, as did 56.3% and 62.1% of respondents who reported concerns about “anxiety, stress, worry about cancer returning” and “changes in body image” respectively. The needs with the highest frequency of reported difficulty seeking help were “changes in sexual intimacy” (88.9%), “changes in relationships with family, partners” (77.8%) and “changes in relationships with friends or coworkers” (75.0%). The needs with the highest reported frequency of being unmet were “changes in sexual intimacy” (66.7%), “changes in relationships with friends or coworkers” (56.3%) and “changes in relationships with family, partners” (55.6%).

Table 16 Descriptive Analysis of Seeking Help and Unmet Needs Within the Emotional Domain for DTC Survivors

Supportive Care Need	No. of responses for help item <sup>1</sup>	Missing Data (%) for help item <sup>2</sup>	Help was sought, <i>n</i> (%)	No. of responses for ease of help item <sup>3</sup>	Had difficulty getting help <i>n</i> , (%) <sup>4</sup>	Unmet Need (%) <sup>4</sup>
Depression, sadness, loss of interest in everyday things	110	5.4	46 (41.8)	59	30 (50.9%)	12 (20.3)
Anxiety, stress, worry about cancer returning	144	7.3	46 (31.9)	64	36 (56.3)	20 (31.3)
Changes in relationships with family, partners	78	3.4	11 (14.1)	18	14 (77.8)	10 (55.6)
Changes in relationships with friends or coworkers	73	2.93	8 (11.0)	16	12 (75.0)	9 (56.3)
Changes in body image (i.e., confidence in appearance, etc.)	105	4.9	17 (16.2)	29	18 (62.1)	12 (41.4)
Changes in sexual intimacy	197	3.9	7 (8.6)	18	16 (88.9)	12 (66.7)

1. The help item is defined as items 45 for the emotional domain.
2. The denominator in calculating the frequency of missing values was 205, representing the total number of surveys collected in the DTC sample.
3. Ease of help item is defined as item 46 for the emotional domain, and responses exclude those who answered “Not a concern” in item 44.
4. The denominator in calculating the frequency of responses was the total number of responses for the ease of help item, excluding missing values.

The three items in the practical domain (Table 17) with the highest reported frequencies for respondents seeking help were “difficulty getting health or life

insurance” (22.2%), “returning to (or future) work or school” (18.4%), and “paying healthcare bills” (14.5%). Of those that reported these as concerns, 89.5% said it was difficult to get help for health or life insurance, 52.0% said it was difficult to get help for returning to work or school, and 60.0% reported difficulty getting help for paying healthcare bills. The supportive care needs in the practical domain with the highest frequency reported for being unmet were “taking care of children, elderly or other family members” (45.5%), “difficulty getting health or life insurance” (36.8%), and “returning to (or future) work or school” (28.0%).

Table 17 Descriptive Analysis of Seeking Help and Unmet Needs Within the Practical Domain for DTC Survivors

<b>Supportive Care Need</b>	<b>No. of responses for help item<sup>1</sup></b>	<b>Missing Data (%) for help item<sup>2</sup></b>	<b>Help was sought, n (%)</b>	<b>No. of responses for ease of help item<sup>3</sup></b>	<b>Had difficulty getting help n, (%)<sup>4</sup></b>	<b>Unmet Need (%)<sup>4</sup></b>
Returning to (or future) work or school	87	4.9	16 (18.4)	25	13 (52.0)	7 (28.0)
Getting to and from appointments	63	4.4	8 (12.7)	9	4 (44.4)	0 (0.0)
Taking care of children, elderly, or other family members	66	3.9	6 (2.9)	11	6 (54.6)	5 (45.5)
Difficulty getting health or life insurances	72	4.4	16 (22.2)	19	17 (89.5)	7 (36.8)

<b>Supportive Care Need</b>	<b>No. of responses for help item<sup>1</sup></b>	<b>Missing Data (%) for help item<sup>2</sup></b>	<b>Help was sought, <i>n</i> (%)</b>	<b>No. of responses for ease of help item<sup>3</sup></b>	<b>Had difficulty getting help <i>n</i>, (%)<sup>4</sup></b>	<b>Unmet Need (%)<sup>4</sup></b>
Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)	69	3.9	10 (14.5)	15	9 (60.0)	3 (20.0)

1. The help item is defined as items 55 for the practical domain.
2. The denominator in calculating the frequency of missing values was 205, representing the total number of surveys collected in the DTC sample.
3. Ease of help item is defined as item 56 for the practical domain, and responses exclude those who answered “Not a concern” in item 54.
4. The denominator in calculating the frequency of responses was the total number of responses for the ease of help item, excluding missing values.

The number of responses and frequency of responses recorded as unmet in the informational domain for the DTC sample are reported in Table 18. The three items with the highest frequency and prevalence of being unmet were information being given about community resources (26.7%), “information about signs of cancer returning” (24.1%), and “information about side effects of treatment” (14.4%).

Table 18 Descriptive Analysis of Unmet Informational Needs for DTC Survivors

<b>Supportive Care Need</b>	<b>No. of responses for item</b>	<b>Unmet Need, <i>n</i> (%)</b>
Information was available to me when I needed it	198	16 (8.1)
I was given information that was useful to me	202	16 (7.9)

<b>Supportive Care Need</b>	<b>No. of responses for item</b>	<b>Unmet Need, <i>n</i> (%)</b>
I was given information in my preferred language	202	4 (2.0)
I was given information about signs of cancer returning	199	48 (24.1)
I was given information about side effects of treatment	202	29 (14.4)
I was given information about community resources	202	54 (26.7)

vi. Comparison of Prevalence of Supportive Care Needs in DTC Sample and CPAC Sample

The frequency of the needs reported in the physical, emotional and practical domains were cross tabulated with the reported severity and are reported in Table 19.

Table 19 Cross Tabulation of Frequency with Severity of Needs in DTC Sample

	<b>Degree of Need, <i>n</i> (%)</b>		
	<b>Severe</b>	<b>Moderate</b>	<b>Mild</b>
<b>Physical Needs</b>			
Swelling of arms or legs	8 (25.0)	13 (40.6)	11 (34.4)
Fatigue, tiredness	65 (40.4)	53 (32.9)	43 (26.7)
Menstrual concerns or fertility concerns	12 (38.7)	13 (41.9)	6 (19.4)
Chronic pain or long-term pain	23 (39.7)	25 (43.1)	10 (17.2)
Bladder and/or urinary problems (i.e., incontinence)	10 (25.0)	15 (37.5)	15 (37.5)

	<b>Degree of Need, <i>n</i> (%)</b>		
	<b>Severe</b>	<b>Moderate</b>	<b>Mild</b>
Gastrointestinal problems (i.e., constipation, diarrhea)	19 (32.8)	24 (41.4)	15 (25.9)
Nerve problems (numbness or tingling in the hands/ feet)	17 (25.8)	24 (37.9)	25 (37.9)
Changes to concentration, memory	28 (32.9)	32 (37.6)	25 (29.4)
Changes in sexual activity or function	12 (22.2)	27 (50.0)	15 (27.8)
<b>Emotional Needs</b>			
Depression, sadness, loss of interest in everyday things	28 (30.1)	36 (38.7)	29 (31.2)
Anxiety, stress, worry about cancer returning	42 (30.2)	45 (32.3)	52 (37.4)
Changes in relationships with family, partners	8 (16.0)	19 (38.0)	23 (46.0)
Changes in relationships with friends or coworkers	8 (19.1)	14 (33.3)	20 (47.6)
Changes in body image (i.e., confidence in appearance, etc.)	25 (29.8)	25 (29.8)	34 (40.5)
Changes in sexual intimacy	17 (32.1)	13 (24.5)	23 (43.4)
<b>Practical Needs</b>			
Returning to (or future) work or school	17 (29.3)	19 (32.8)	22 (37.9)
Getting to and from appointments	3 (10.0)	9 (30.0)	18 (60.0)
Taking care of children, elderly, or other family members	5 (14.7)	11 (32.4)	18 (52.9)

	Degree of Need, <i>n</i> (%)		
	Severe	Moderate	Mild
Difficulty getting health or life insurances	21 (48.8)	14 (32.6)	8 (18.6)
Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)	8 (19.5)	16 (39.0)	17 (41.5)

Additionally, the frequency of needs reported by DTC survivors was also cross tabulated with whether respondents had difficulty obtaining help (Table 20).

Table 20 Cross Tabulation of Frequency of Needs in DTC Survivors with if Respondents Had Difficulty Obtaining Help

	Had Difficulty Obtaining Help, <i>n</i> (%)	Did Not Have Difficulty Obtaining Help, <i>n</i> (%)
<b>Physical Needs</b>		
Swelling of arms or legs	14 (58.3)	10 (41.7)
Fatigue, tiredness	65 (64.4)	36 (35.6)
Menstrual concerns or fertility concerns	11 (55.0)	9 (45.0)
Chronic pain or long-term pain	25 (59.5)	17 (40.4)
Bladder and/or urinary problems (i.e., incontinence)	13 (46.4)	15 (53.6)
Gastrointestinal problems (i.e., constipation, diarrhea)	14 (35.9)	25 (64.1)
Nerve problems (numbness or tingling in the hands/ feet)	25 (61.0)	16 (39.0)
Changes to concentration, memory	33 (75.0)	11 (25.0)
Changes in sexual activity or function	16 (69.6)	7 (30.4)

	<b>Had Difficulty Obtaining Help, <i>n</i> (%)</b>	<b>Did Not Have Difficulty Obtaining Help, <i>n</i> (%)</b>
<b>Emotional Needs</b>		
Depression, sadness, loss of interest in everyday things	30 (50.8)	29 (49.2)
Anxiety, stress, worry about cancer returning	36 (57.1)	27 (42.9)
Changes in relationships with family, partners	14 (77.8)	4 (22.2)
Changes in relationships with friends or coworkers	12 (75.0)	4 (25.0)
Changes in body image (i.e., confidence in appearance, etc.)	18 (62.1)	11 (37.9)
Changes in sexual intimacy	15 (88.2)	2 (11.8)
<b>Practical Needs</b>		
Returning to (or future) work or school	13 (52.0)	12 (48.0)
Getting to and from appointments	4 (44.4)	5 (55.6)
Taking care of children, elderly, or other family members	6 (54.5)	5 (45.5)
Difficulty getting health or life insurances	17 (89.5)	2 (10.5)
Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)	8 (57.1)	6 (42.8)

The prevalence of supportive care needs with the corresponding proportions and chi-squared test statistics in both the DTC samples and the comparative samples are listed in Table 21, and Figures 7, 8 and 9. For cell counts that contain less than 20 respondents, or an expected frequency of less than 5 in one cell, Fisher's exact testing was also done and recorded. Of the Pearson  $\chi^2$  tests done, only the test done to compare the proportion of responses for "fatigue, tiredness" had a large enough sample size for 80% power at 95% significance. This found

that there was a significant difference in the proportion of respondents reporting “fatigue, tiredness” in the DTC sample in comparison to 2016 CPAC comparative sample ( $\chi^2 = 22.5412$ ,  $p$ -value= 0.000).

Table 21 Cross Tabulations for Individuals’ Needs with Prevalence of Presence with Associated Pearson  $\chi^2$  Test Statistics for DTC Survivors and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors

	<b>Proportion Endorsing Need in DTC Sample (%)</b>	<b>Proportion Endorsing Need in Comparative Sample (%)</b>	$\chi^2$	$p$ -value <sup>1</sup>
<b>Physical Needs</b>				
Swelling of arms or legs	32/197 (16.24)	289/1374 (21.03)	2.4314	0.119
Fatigue, tiredness	161/198 (81.31)	900/1400 (64.29)	22.5412	0.000
Menstrual concerns or fertility concerns	31/193 (16.06)	293/1352 (21.67)	3.2065	0.073
Chronic pain or long-term pain	58/197 (29.44)	411/1378 (29.83)	0.0122	0.912
Bladder and/or urinary problems (i.e., incontinence)	40/200 (20.00)	438/1392 (31.47)	10.9417	0.001
Gastrointestinal problems (i.e., constipation, diarrhea)	58/197 (29.44)	464/1386 (33.48)	1.2712	0.260
Nerve problems (numbness or tingling in the hands/feet)	66/197 (33.50)	435/1385 (31.41)	0.3497	0.554
Changes to concentration, memory	85/197 (43.15)	452/1384 (32.66)	0.4580	0.004
Changes in sexual activity or function	54/198 (27.27)	591/1403 (42.12)	15.9083	0.000

	<b>Proportion Endorsing Need in DTC Sample (%)</b>	<b>Proportion Endorsing Need in Comparative Sample (%)</b>	$\chi^2$	<i>p</i> -value <sup>1</sup>
<b>Emotional Needs</b>				
Depression, sadness, loss of interest in everyday things	93/201 (46.27)	536/1273 (42.11)	1.2300	0.267
Anxiety, stress, worry about cancer returning	139/200 (69.50)	822/1280 (64.22)	2,1188	0.146
Changes in relationships with family, partners	50/200 (25.00)	412/1425 (28.91)	1.3193	0.251
Changes in relationships with friends or coworkers	42/200 (21.00)	228/1416 (16.10)	3.0215	0.082
Changes in body image (i.e., confidence in appearance, etc.)	84/198 (42.42)	516/1412 (36.54)	2.5684	0.109
Changes in sexual intimacy	53/199 (26.63)	562/1411 (39.83)	12.8659	0.000
<b>Practical Needs</b>				
Returning to (or future) work or school	58/199 (29.15)	264/1387 (19.03)	10.9774	0.001
Getting to and from appointments	30/197 (15.23)	236/1411 (16.73)	0.2807	0.596
Taking care of children, elderly, or other family members	34/199 (17.09)	153/1393 (10.98)	6.2541	0.012
Difficulty getting health or life insurances	43/199 (21.61)	184/1388 (13.26)	9.9035	0.002
Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)	41/199 (20.60)	265/1405 (18.86)	0.3426	0.558

1. For any cell counts <20, the *p*-value reported is for Fisher's exact test.

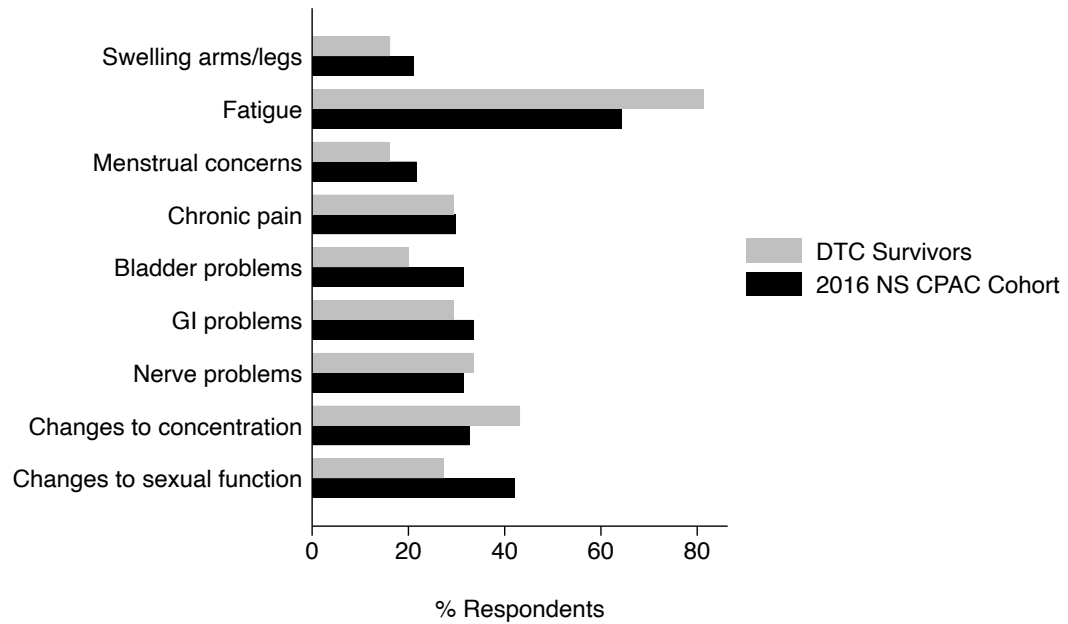
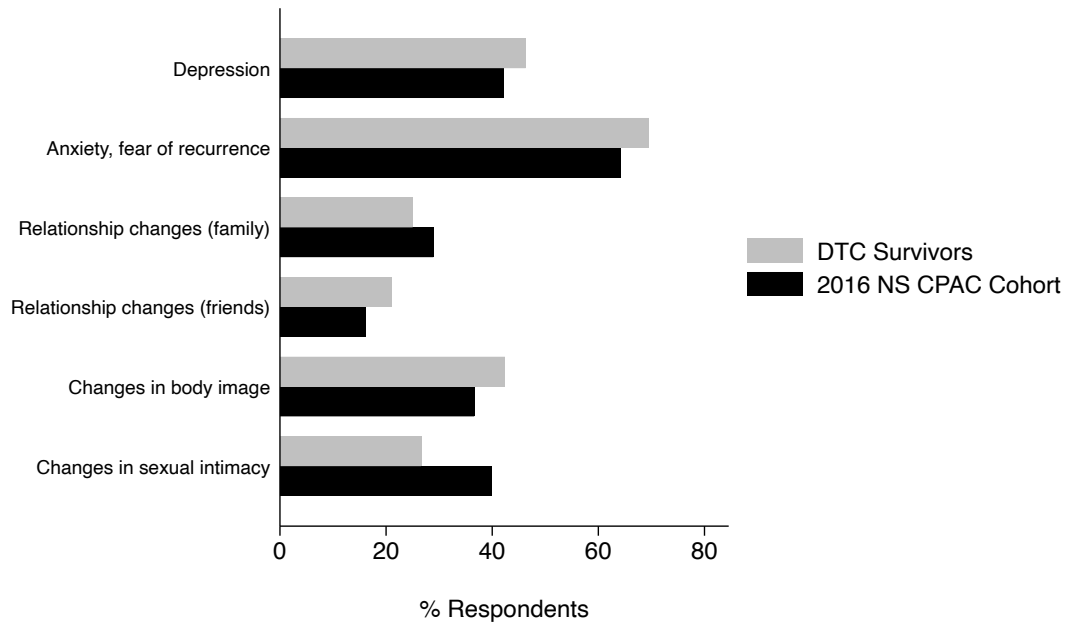


Figure 7 Proportion of Respondents Endorsing Physical Needs from DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors



**Figure 8** Proportion of Respondents Endorsing Emotional Needs from DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors

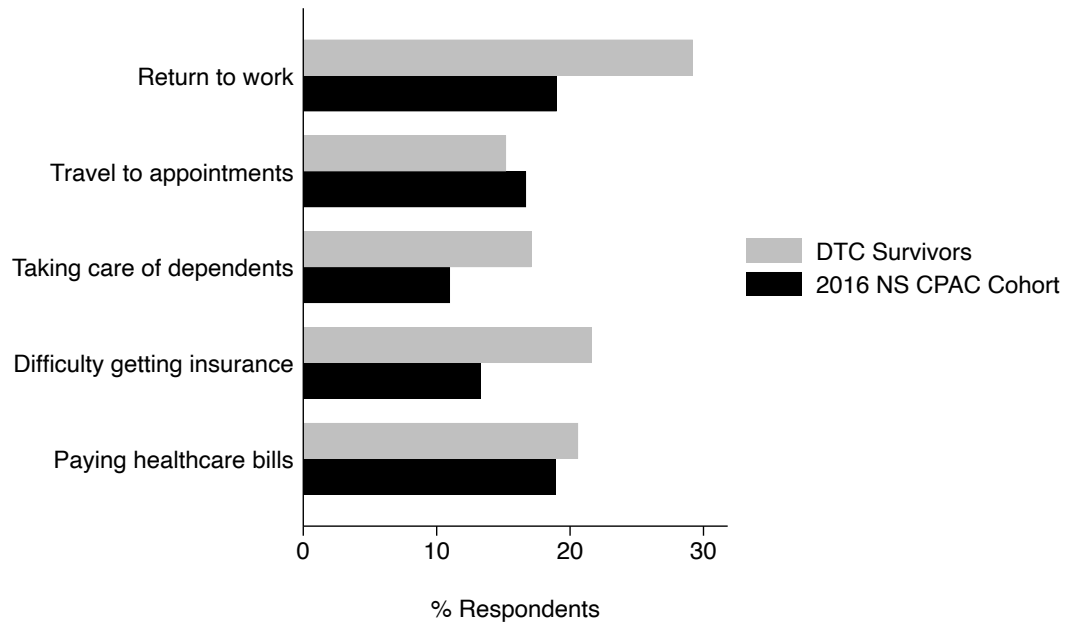


Figure 9 Proportion of Respondents Endorsing Practical Needs from DTC Survivor Sample and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors

Pearson  $\chi^2$  tests and Fisher's exact testing were also done to compare the proportions of respondents reporting unmet needs in the DTC sample and the comparative sample. These results for the physical, emotional, practical and informational domains are reported in Table 22. None of the comparative tests done had large enough sample sizes to adequately power the tests at 95% significance.

Table 22 Cross Tabulations for Individuals Needs with Prevalence of Unmet Needs with Associated Pearson  $\chi^2$  Test Statistics for DTC Survivors and Comparative Sample of Breast Cancer, Colorectal Cancer, Prostate Cancer, Melanoma, Hematologic Malignancies and Other Cancer Survivors

	<b>Proportion Endorsing Unmet Need in DTC Sample (%)</b>	<b>Proportion Endorsing Unmet Need in Comparative Sample (%)</b>	$\chi^2$	<b>p-value<sup>1</sup></b>
<b>Physical Needs</b>				
Swelling of arms or legs	7/25 (28.00)	225/428 (52.57)	5.7071	0.022
Fatigue, tiredness	34/102 (33.33)	259/550 (47.09)	6.5816	0.010
Menstrual concerns or fertility concerns	4/21 (19.05)	216/353 (61.19)	14.5330	0.000
Chronic pain or long-term pain	8/43 (18.60)	229/456 (50.22)	15.7493	0.000
Bladder and/or urinary problems (i.e., incontinence)	5/28 (17.86)	185/419 (44.15)	7.4261	0.006
Gastrointestinal problems (i.e., constipation, diarrhea)	4/39 (10.26)	179/453 (39.51)	13.1585	0.000
Nerve problems (numbness or tingling in the hands/ feet)	11/42 (26.19)	220/405 (54.32)	12.0587	0.001
Changes to concentration, memory	20/46 (43.48)	225/315 (71.43)	14.3789	0.000
Changes in sexual activity or function	12/23 (52.17)	225/431 (52.20)	0.000	1.000
<b>Emotional Needs</b>				
Depression, sadness, loss of interest in everyday things	12/59 (20.34)	185/362 (51.10)	19.2872	0.000
Anxiety, stress, worry about cancer returning	20/64 (31.25)	200/423 (47.28)	5.7684	0.016

	<b>Proportion Endorsing Unmet Need in DTC Sample (%)</b>	<b>Proportion Endorsing Unmet Need in Comparative Sample (%)</b>	$\chi^2$	<b>p-value<sup>1</sup></b>
Changes in relationships with family, partners	10/18 (55.56)	236/325 (72.62)	2.4473	0.175
Changes in relationships with friends or coworkers	9/16 (56.25)	221/245 (90.20)	16.5433	0.001
Changes in body image (i.e., confidence in appearance, etc.)	12/29 (41.38)	226/322 (70.19)	10.1135	0.003
Changes in sexual intimacy	12/18 (66.67)	237/387 (61.24)	0.2139	0.806
<b>Practical Needs</b>				
Returning to (or future) work or school	7/25 (28.00)	185/267 (69.29)	17.3057	0.000
Getting to and from appointments	0/9 (0.00)	135/264 (51.14)	9.1045	0.003
Taking care of children, elderly, or other family members	5/11 (45.45)	168/214 (78.50)	6.4311	0.021
Difficulty getting health or life insurances	7/19 (36.84)	171/221 (77.38)	15.0028	0.000
Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)	3/15 (20.00)	160/258 (62.02)	10.4019	0.002
<b>Informational Needs</b>				
Information was available to me when I needed it	16/198 (8.08)	84/1427 (5.89)	1.4497	0.267
I was given information that was useful to me	16/202 (7.92)	84/1419 (5.92)	1.2233	0.273
I was given information in my preferred language	4/202 (1.98)	19/1415 (1.34)	0.5123	0.519

	<b>Proportion Endorsing Unmet Need in DTC Sample (%)</b>	<b>Proportion Endorsing Unmet Need in Comparative Sample (%)</b>	$\chi^2$	<b>p-value<sup>1</sup></b>
I was given information about signs of cancer returning	48/199 (24.12)	250/1415 (17.67)	4.8254	0.028
I was given information about side effects of treatment	29/139 (20.86)	110/1418 (7.76)	9.8160	0.002
I was given information about community resources	54/202 (26.73)	218/1405 (15.52)	15.8023	0.000

1. For any cell counts <20, the p-value reported is for Fisher's exact test.

vii. Sensitivity Analyses

The age and gender for all 375 individuals with DTC sent a research package were collected. The prevalence and frequency for the age group and gender of individuals with DTC who were contacted for the study are listed in Table 23.

Table 23 Descriptive Analysis of Demographic Variables Age Categories and Gender for All Potential Survey Participants Sent a Research Package

<b>Variable</b>	<b>All potential survey participants</b>	
	<b>Number</b>	<b>Frequency (%)</b>
<b>Age</b>		
Under 18	0	0
18 to 24	2	0.5
25 to 34	8	2.1
35 to 44	43	11.5
45 to 54	79	21.1
55 to 64	109	29.1
65-74	89	23.7

Variable	All potential survey participants	
	Number	Frequency (%)
75-84	40	10.7
85 or over	5	1.3
<b>Gender</b>		
Male	72	19.2
Female	303	80.8

The presence of “fatigue, tiredness” as a need in the DTC sample was also cross tabulated by time after diagnosis (Table 24). Overall, 90.5% of individuals diagnosed within the last 5 years reported the presence of “fatigue, tiredness” as a concern, compared to 74% of individuals diagnosed between 5 to 10 years ago, and 82.2% of individuals diagnosed more than 10 years ago.

Table 24 Cross Tabulation of Proportion Endorsing Fatigue in DTC Survivors with Years After Diagnosis

	Diagnosed <5 Years	5-10 years since diagnosis	>10 years since diagnosis
<b>Proportion Endorsing Fatigue (%)<sup>1</sup></b>	38/42 (90.5%)	54/73 (74.0%)	60/73 (82.2%)

1. Ten respondents who answered “fatigue, tiredness” item did not report diagnosis year, and are not included.

#### viii. Missing Data

Of the demographic and related variables evaluated for the DTC sample, the items with the highest frequency of missing data were employment status (5.4%), population size of residence (4.4%), yearly household income (3.4%) and education (2.4%). For treatment-related variables that were assessed, the items

with the highest frequency of missing data were diagnosis year (5.4%) and presence of metastatic disease (3.4%).

In the physical domain, the item with the highest frequency of missing data for whether a need was present was “menstrual concerns or fertility concerns” (5.6%). The item with the most missing values for whether a need was present was “changes in body image” (3.4%) in the emotional domain and “getting to and from appointments” (3.9%) in the practical domain. The range for the frequency of missing data for the presence of needs varied between 2.4% to 5.9% in the practical domain, between 2.0% and 3.4% in the emotional domain, and between 2.9% and 3.9% in the practical domain.

For the number of responses indicating whether help was sought, the range for the frequency of missing values in the physical domain was between 3.4% and 11.2%. The needs with the most amount of missing data for whether help was sought in the physical domain were “menstrual concerns or fertility concerns” and “bladder and/or urinary incontinence”. The frequency of missing data for whether help was sought ranged between 2.9% to 7.3% for the emotional domain and between 3.9% to 4.4% for the practical domain. The needs with the most missing data in the emotional and practical domains about whether help was sought were “anxiety, stress, worry about cancer”, “getting to and from appointments” and “paying healthcare bills”. For the informational domain, the item with the most

missing responses was “I was given information about the signs of cancer recurring” (2.9%).

## CHAPTER 7 DISCUSSION

Our response rate of 54.6% closely matches the response rate of 44.6% in the Nova Scotia cohort of the 2016 CPAC study (85) and exceeded the national average of 33.3% (25). As expected, our study sample of DTC survivors had a higher proportion of female respondents and skewed younger in comparison to the 2016 CPAC study sample. There was a slight preponderance to a more urban dwelling population, and higher rates of university education in the DTC sample. Almost 80% of the surveys were returned back as a physical copy, which also closely matches what was reported for the 2016 CPAC study (85).

Sensitivity analyses comparing the age and gender of all individuals contacted to participate in the survey compared to the self-reported data of survey participants (Table 23) showed a slight over-representation of individuals aged 65 to 74 years old who responded, but with otherwise only minimal differences. Overall, we observed many similarities between the current DTC survivor cohort and the 2016 CPAC sample with respect to demographic characteristics and response rate, further strengthening the validity of our findings.

There were a few key differences between the DTC and comparative CPAC samples. For example, to have an adequate sample size with which to compare the CPAC 2016 study sample with, we did not restrict the inclusion criteria for the DTC sample based on time after treatment, as had been done for the CPAC sample. Therefore, as expected, there was a difference observed in the length of

time after initial treatment between the DTC sample and the 2016 CPAC study sample. Most of the respondents in the CPAC study sample (91.2%) reported being diagnosed between 2012 and 2014, whereas for the DTC survivor sample, the most common self-reported year of diagnosis was prior to 2010. However, the sensitivity analysis stratifying respondents by years since diagnosis (Table 24) did not show any significant differences in the major findings of this study, suggesting the expanded criteria for length of time since treatment did not seem to affect the responses.

The results of this study broadly confirm our hypothesis that DTC survivors have ongoing supportive care needs in a similar pattern and frequency compared to breast, colorectal, prostate and other cancer survivors in Nova Scotia. About 8 out of 10 respondents reported at least one concern in the physical and emotional domains, and 3 out of 10 respondents reported at least one need in the practical domain, which matches what has previously been reported in other cancer survivors (25,81,85). The most reported needs for the DTC sample in the physical, emotional and practical domains of “fatigue, tiredness”, “anxiety, stress, worry about cancer returning” and “returning to (or future) work or school”, respectively, was also consistent with what was previously reported (81). These results broadly suggest that Nova Scotian cancer survivors, including DTC survivors, have ongoing physical, emotional, informational and practical needs post-treatment, most of which are currently not being addressed while they are transitioning to primary care.

The most endorsed need within the physical domain for both the DTC and comparative samples was “fatigue, tiredness”. Cancer related fatigue is well-documented, and its severity is known to differ by cancer type and treatment phase (133,134). However, there were key differences in the severity and the prevalence of fatigue reported in DTC survivors, which may be unique to this population relative to other cancer survivors. The first was that a significantly greater proportion of DTC survivors endorsed “fatigue, tiredness” as a need compared to other cancer survivors in Nova Scotia (81.3% vs 64.2%, respectively). Our reported prevalence of fatigue is also much higher than what has been previously reported in cross-sectional studies of DTC survivors. For example, Maki et al. (2022) reported the prevalence of fatigue was about 44% in a cohort of DTC survivors (102). Additionally, a plurality of DTC respondents reported fatigue as a “severe” or “moderate” concern, suggesting that DTC survivors suffer from a high degree of fatigue.

Interestingly, the higher prevalence of “fatigue, tiredness” in the DTC sample exists despite the average length of time posttreatment at the time of survey being much longer than the comparative sample. Additionally, in the sensitivity analysis looking at the prevalence of “fatigue, tiredness” based on time since diagnosis, it was found that the proportion of DTC survivors endorsing “fatigue, tiredness” remained consistently high across time. The stability of what has been termed *persistent posttreatment fatigue* as a concern in DTC survivors has also

been previously reported (135). Despite recognition of this phenomenon, there is a paucity of evidence for the effective management of fatigue in DTC survivors specifically, and it is not known if treatments for general cancer related fatigue, such as physical activity, translate to this population (102,136). This study adds to a small, but convincing, set of data that fatigue is a major concern for DTC survivors. Additionally, this is the first study in the Canadian context of which we are aware of to find that fatigue is more prevalent in DTC survivors compared to other cancer survivors.

Another interesting trend observed was the higher proportion of DTC survivors endorsing “concentration, memory changes” in comparison to other cancer survivors. While we did not have the sample size to determine whether the difference was significant, it was still notable as the sample DTC population is younger on average than the comparative sample and because a large frequency of respondents reported difficulty getting help for this concern.

Interestingly, these findings replicate some smaller studies showing that DTC survivors suffer from and perceive cognitive issues at rates higher than the general population (137) and even other cancer survivors (95). While we do not wish to further speculate as to the causality of this trend at this time, we believe that it warrants further investigation, especially as there are very little resources dedicated for this particular concern (104).

DTC survivors reported lower rates of “changes in sexual intimacy”, “changes in sexual activity or function” and “bladder concerns and/or urinary problems” compared to the 2016 Nova Scotian CPAC cohort. This was an expected finding given the high proportion of prostate cancer survivors in the comparative sample (85) and the relatively lower age of the respondents in the DTC sample. Urinary incontinence, erectile dysfunction (138) and changes in sexual intimacy (139) are well known long-term side effects of prostate cancer treatments. Urinary incontinence concerns are also known to increase with age in the general population (140,141). These differences further support the validity of the study findings, as they demonstrate that the survey was sensitive enough to distinguish between the known concerns of various cancer survivors.

Surprisingly, despite the well-known associations of thyroid hormone function with weight changes and menstrual irregularities, there were no significant differences in the proportions of respondents in the DTC sample and comparative sample endorsing “changes in body image” or “menstrual concerns or fertility concerns”. One possible explanation is that individuals with these concerns may not have necessarily attributed them to their thyroid cancer, and therefore it was not captured in their responses. Alternatively, it may also be possible that our sample size was not large enough to adequately detect an effect or difference in these concerns. Interestingly, the survey was also supplemented by qualitative responses (data not reported) where many respondents who did endorse concerns of this nature described their experiences in narrative form. Therefore,

the lack of qualitative data analysis in this study may be responsible for missing important contextual information on this issue, so further analysis is yet needed.

Similar proportions of “depression, sadness, loss of interest in everyday things” and “anxiety, stress, worry about cancer returning” were also commonly reported by respondents as ongoing needs in both the DTC and comparative sample. The preponderance of mental health concerns in cancer survivors is sadly well known. Many national organizations, including the American Society of Clinical Oncology, have developed guidelines recommending specific screening and treatment options for the long-term psychological effects of cancer, and several studies have shown that depression and anxiety disorders are often underdiagnosed in this population (142). Our study results reinforce that these emotional concerns are common in all cancer survivors. However, some large scale, national cohort studies have suggested that the prevalence of anxiety and depression are comparable to that of the general population, and thus the causality between a history of cancer and mental health concerns remains unclear (143).

The high prevalence of self-reported “anxiety, stress, worry about cancer returning” in this study could also be attributed to concerns of fear of recurrence, which is a known concern for cancer survivors particularly in the transition phase (25), including DTC survivors (144). Fear of recurrence has been defined as “fear, worry or concern relating to the possibility that the cancer will come back

again” (145) and is one of the most common unmet needs for cancer survivors (146). At low levels, this may be protective, as it promotes positive health behaviours such as attending check-up appointments (145). However, at clinically significant levels, fear of recurrence been linked to decreased HRQoL in DTC survivors compared to the general population (147). Due to the compound nature of the wording in this study, we are unable to attribute the high self-reported prevalence “anxiety, fear of cancer returning” to fear or recurrence alone.

In the practical domain, the most common needs endorsed were “returning to (or future) work or school” and “difficulty getting life insurance” in both the DTC sample and the comparative sample. While the number of responses in the DTC sample did not allow for significance to be tested, the proportion of respondents endorsing this need was higher in the DTC sample compared to the comparative sample. As previously reported in other studies (118,148), one explanation could relate to the younger age of the respondents in the DTC sample at diagnosis, as they would not qualify for provincial prescription drug coverage afforded to seniors aged 65 and older (149). Furthermore, many respondents who reported difficulty getting life insurance as a concern said it was difficult to get help, or that they got no help at all, suggesting that there is a serious gap in much needed supports for this population.

Similarly, in the informational domain there were higher proportions of respondents in the DTC sample reporting unmet needs relating to “information about side effects of treatment” and “information about community resources”, although the number of respondents did not support statistical testing. While it is well-known that DTC survivors have ongoing informational needs about treatment and management likely due to the lifelong nature of hormonal replacement and testing (116), the finding that they have a higher rate of concern for community resources is a novel one. One possible explanation could be the heterogeneity of the DTC sample across variable treatment times, as some resources may not have existed or been provided to individuals who have been transitioned to primary care. Another explanation could be the specific nature of the care received by the DTC survivors in this study. In other words, as much of the DTC care was previously centrally done by the ITOC team until recently, the supports available for DTC survivors may not be as well developed or disseminated. Further analysis of the qualitative comments provided as part of the study and additional focus groups may help to provide the additional context needed for these findings.

While proportions for the unmet needs were calculated for the DTC sample and then compared to other cancer survivors as has been previously reported, the number of responses were too few to conduct Pearson  $\chi^2$  testing at 80% power for 95% significance, and we cannot speculate on the results further due to the high risk of random error within the findings.

## **7.2 Strengths and Limitations**

There are several strengths to this study. The first is that the sample population appears to be highly representative of the intended study population, and that we had a relatively high response rate of 54.6% (compared to national average of 33.3% in 2016 CPAC study), which we believe leads to a more representative viewpoint of the concerns faced by DTC survivors in Nova Scotia. This high degree of capture likely derives from working directly with the ITOC clinic, while still following pre-established protocols from the 2016 CPAC study. Additionally, as the surveys were mailed together with an online option, we expect there is good representation from survey respondents who may not be traditionally well captured, including rural populations, younger respondents and individuals who do not seek access to primary care/traditional health care services. Additionally, as the methodology is meant to capture concerns from a patient's perspective, this study also documents cancer survivors needs and symptoms that are not typically addressed in the DTC survivorship literature, but still cause mental anguish. This may be because they have concerns that do not reach a level of clinical significance felt to be diagnostic, or because these concerns are dismissed and not linked to their cancer diagnoses. Finally, as we utilized the same study protocol and study instrument used in the 2016 CPAC study, we were able to present the findings in DTC survivors in comparison to other cancer survivors. This allowed for further examination and exploration into whether

these concerns being reported are disease specific or generalizable to all other cancer types.

Despite numerous strengths, there are several limitations to this study as well. Firstly, there was a high degree of missing data, which was expected given the previous experience of the CPAC study team which used a similar methodology. Items regarding household income, population size of residence and education, had more missing values than other items about self-reported demographic variable, suggesting that they are not missing at random. Missing data were also an issue for the data about the various needs across domains, whether help was sought and whether those needs were unmet. One hypothesis is that the wording of the items confused survey participants, who believed that if they did not have to complete the remaining items about seeking help or if a need was unmet if they endorse the need being asked about. As in the last CPAC study, missingness appears to be more common towards the end of the survey, with items in the practical domain having the highest average frequency of missing data in comparison to the physical symptom domain, suggesting response fatigue as well.

Another major limitation to this study is that due to the anonymous nature of the data collection, self-reported concerns of thyroid cancer survivors cannot be linked to thyroid hormone function testing at an individual level. It is well known that thyroid dysfunction in the form of hyper- and hypothyroidism can both cause

fatigue (150,151). These abnormalities in thyroid hormone levels can result from either iatrogenic TSH suppression (90) or non-adherence to thyroid hormone replacement in DTC survivors (152). Many studies have shown that post-treatment fatigue is more common in DTC survivors compared to the general population, and other oncological controls (153). While some small studies have reported reduced QoL and persistent posttreatment fatigue in DTC survivors independent of thyroid function (154–157), the evidence overall remains conflicting (102,158). Further research that collects TSH levels together with self-reported fatigue may be helpful to more definitively answer this important question.

To preserve comparability, the items were not worded to be specific to thyroid cancer, and therefore we could not ask questions about other known concerns for thyroid cancer survivors, such as hair and skin changes. While several qualitative items in the survey did invite participants to report other needs and concerns, the analysis of these responses is beyond the scope of the present thesis work. As a result, the full array of needs experienced by the DTC survivor population surveyed could not be reported or analyzed alongside those that were documented in this work.

While every precaution was taken to verify the addresses of potential study participants, it is unknown whether non-responses were due to the survey package not reaching the intended recipient, not being delivered or individuals

deciding not to participate in the study. While the sensitivity analyses did show a similar age and gender spread in the overall sample to the self-reported data from actual survey participants, we were unable to perform similar verification for other important sociodemographic factors, including household income and urban/rural location of residence. Similarly, the reliance on self-reported data in this study, while necessary to capture the patient experience, also introduces legitimate concerns about the reliability of the data. One example is that only 69% of survey respondents reported taking thyroid hormone replacement as a treatment, even though this is standard of care for the vast majority of DTC survivors after thyroidectomy (159,160), and should approach 100%. This may be due to confusion stemming from the survey layout and/or wording, as other variables which we did verify (“age” and “gender”) matched closely to what was expected. Similarly, 6.6% of DTC respondents reported that they had metastatic disease at diagnosis, even though potential respondents were known, by exclusion criteria, to not have metastatic disease. Interestingly, a similar proportion (5.3%) of respondents in the 2016 CPAC group also reported having been diagnosed with metastatic disease, despite study criteria also excluding this.

Another limitation is that the comparisons between the DTC sample and other cancer survivors may be affected by differences in temporality, disease experiences, system-related issues and other factors given the wide degree of heterogeneity in the populations surveyed. In particular, the COVID-19

(Coronavirus disease 2019) pandemic and associated lockdowns between 2020 to 2021 were associated with major health-systems related changes, and has been linked to negative patient perceptions of care delivery and disease (161–163). To preserve comparability, the survey that was sent to DTC respondents contained instructions to disregard needs related to COVID-19, however given the magnitude of the effects on the healthcare system (164), we consider it was inevitable that post-pandemic related changes would have affected patients' responses in some form.

Finally, as previously outlined, one of the biggest differences in the DTC and comparative sample was the self-reported dates of diagnoses, with most of the respondents in the DTC sample having been diagnosed more than 10 years ago in comparison to the CPAC sample, which surveyed individuals treated only one to three years prior to the study. To mitigate this, we conservatively kept the threshold for the difference in proportions for the presence of a supportive care need to be relatively high at 20%, to assess for only very large differences. The only supportive care need that we were adequately powered to detect a significant difference in proportions was for “fatigue, tiredness”. Furthermore, we did additional sensitivity analyses to look at the presence of the concern over treatment time (Table 24), to ensure there were no large differences and that this was not related to any recency bias. While the other trends that arose while comparing the different samples appear of interest, and warrant further

investigation, we were careful not to draw any conclusions, instead treating these only as hypothesis generating findings for future study and evaluation.

#### **7.4 Implications**

This important study is the first to demonstrate in the Canadian population how the supportive care needs of thyroid cancer survivors compare to those of other cancer survivors during the transition period to primary care. The results of this study will form an important basis upon which future research will be conducted. Currently, a prospective multi-centre study is being planned, which will use the results of this study to deliver robust, national data about the feasibility of transitioning these survivors to primary care. Planning for a follow-up study to link the results of this work with clinical outcome data and biochemical testing is also underway. Finally, the collection of primary data will allow for further novel research within the surveyed population, as has been done for other cancer survivors from the 2016 CPAC Transitions Study. These could include an analysis of the qualitative responses, assessing thyroid hormone replacement concerns and examining psychosocial factors associated with unmet needs within this population.

As the development of this study directly involved existing stakeholders and policymakers directly through partnership with the ITOC team, we anticipate a high impact and rapid uptake of the study results. The results of this study will have clear relevance to both DTC survivors and the development of clinical care pathways to transition these patients to long-term follow-up within the community.

Examples of policies that will be directly informed by these results will include the tailoring of SCPs, standardization of communication to PCPs about long-term concerns of DTC survivors and the development of targeted interventions such as educational sessions and patient-centered counselling for DTC survivors during the transition process to reduce distress in this population.

Another important contextual factor for this study has been the sudden and sharp rise in the number of individuals without a regular PCP in Nova Scotia since 2016 (165). Per informal feedback based on the ITOC team's clinical experience, the rising number of patients seen without a family doctor has been the main barrier in transferring DTC survivors for community-led follow-up care. While the results of this study are important toward understanding the patient experience for DTC survivors and helping to create educational resources for providers, we also clearly recognize that there are current structural limitations within the healthcare system that must also be concurrently addressed to improve the transition of care for these patients.

## **7.5 Conclusions**

DTC survivors in Nova Scotia continue to report ongoing supportive care needs well after treatment as they transition to primary care-led follow-up. While the prevalence of supportive care needs is broadly similar to those reported from breast cancer, colorectal cancer, prostate cancer and other cancer survivors, there are still key differences. These include a significantly higher proportion of DTC survivors reporting fatigue as a supportive care need in comparison to other cancer survivors, suggesting that this may be a disease specific concern. This is the first study in Canada to document that the prevalence of reported fatigue is higher in DTC survivors compared to other cancer survivors using a robust PROM-based approach. Further work is underway to evaluate the supportive care needs of DTC survivors transitioning to primary care-led models of follow-up in Nova Scotia on a prospective basis to better optimize health outcomes for this population.

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## APPENDIX A SAMPLE OF MODIFIED CANCER TRANSITION SURVEY

### Transitions Survey

We need **your help to improve the quality of thyroid cancer care** for patients/survivors across Canada. When cancer treatment ends, many patients need follow-up care. Patients often have questions about what happens next, what changes in their lives, and where to go to seek help. Some changes are emotional, while others are physical and may include ongoing side effects from cancer treatment.

The purpose of the survey is to gather feedback to better understand the experiences of people who have completed thyroid cancer treatment and are going through **follow-up thyroid cancer care**. The results from the survey will help to improve the health care system.

As someone who has been diagnosed and treated for thyroid cancer, you have first-hand experience of the kinds of supports that people need as they transition back to their lives after cancer treatment.

For this survey, we ask you to think only about the time period after completing cancer treatments such as surgery or radioactive iodine therapy (I-131).

- Your opinions are important. Please be **honest** about your experiences after thyroid cancer treatment.
- Everything you tell us will be kept completely **confidential**. Your individual responses will never be shared with your health care team.
- This survey is **voluntary**. If you choose not to complete the survey, your health care services will not be affected in any way.
- This survey will take about **45 minutes** to complete but please take as long as you need to.

If you need help to complete this survey, please ask a family member, caregiver or a friend to assist you. If you have **questions or concerns** when filling in this survey, please contact the Principal Investigator, Dr. Fatima Imran, at [fimran@dal.ca](mailto:fimran@dal.ca).

**Thank you for taking the time to participate in this study. Your responses are very valuable and will help improve health care services!**

Please complete the survey either **online** OR on **paper**.

- ✓ If you complete the survey on **paper**, please return your completed survey in the large pre-paid envelope addressed to the Interdisciplinary Thyroid Oncology Clinic.
- ✓ Please do not include any names or personal information in your responses.

# Transitions Survey

Please answer the questions below by putting an X in ONE BOX for each question unless more than one answer is allowed (these questions are clearly marked).

If you would prefer to complete the survey online, please go to:

<https://research-study.nshealth.ca/surveys/?s=AJP4HK4R9XNXJAMJ> and enter your online PIN. This PIN is unique to you, which means that you can begin completing the survey, take a break if you like, and return to the same spot – all your answers will be saved.

## Information about you

**1** Are you completing the survey...?

- For yourself
- For someone else

**2** Are you...?

- Male
- Female
- Other (specify): \_\_\_\_\_
- Prefer not to answer

**3** How old are you?

- Under 18            55 to 64
- 18 to 24            65 to 74
- 25 to 34            75 to 84
- 35 to 44            85 or over
- 45 to 54            Prefer not to answer

**4** Are you currently...?

- Single (never married)
- Married
- Partnered (living with someone)
- Separated
- Divorced
- Widowed
- Prefer not to answer

**5** Including yourself, how many people live in your household?

- I live alone
- 2
- 3
- 4
- 5 or more

**6** How many children under 18 years old do you have?

- No children under 18 years old
- 1 child
- 2 children
- 3 or more children
- Prefer not to answer

**7** Do you currently provide support or care for an adult friend or family member? That is, is there anyone you regularly help with household chores, take to appointments, or help with finances, etc.?

- Yes
- No

## Your health and well-being

**8** How would you describe your overall quality of life today?

- Very good
- Good
- Fair
- Poor
- Very poor

**9** In general, would you say your...

	physical health is...	emotional health is...
Very good	<input type="checkbox"/>	<input type="checkbox"/>
Good	<input type="checkbox"/>	<input type="checkbox"/>
Fair	<input type="checkbox"/>	<input type="checkbox"/>
Poor	<input type="checkbox"/>	<input type="checkbox"/>
Very poor	<input type="checkbox"/>	<input type="checkbox"/>

**10** Did you have any of the following chronic conditions before you were diagnosed with cancer?

If you've been diagnosed with more than one type of cancer, please think about the chronic conditions you had **prior to your most recent cancer diagnosis**.

Please X all boxes that apply to you

- No chronic conditions
- Arthritis, osteoarthritis, or other rheumatic disease
- Cardiovascular or heart condition; hypertension or high blood pressure
- Chronic kidney disease
- Diabetes
- Osteoporosis
- Respiratory diseases (such as asthma or COPD - chronic obstructive pulmonary disease)
- Mental health issues (such as depression or anxiety)
- Other chronic condition. Specify type:  
\_\_\_\_\_

**11** Different people have different ways of doing things, regardless of their health. Generally, how easy or hard do you find each of the following?

Please X one box in each row

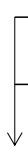
	Very easy	Easy	Neither easy nor hard	Hard	Very hard
Coping with challenges in your day-to-day life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sharing your worries or concerns with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asking doctors questions about your concerns related to follow-up cancer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## About your history with thyroid cancer

This survey is about your experiences following the completion of cancer care treatment.

**12 Have you ever been diagnosed with more than one type of cancer?**

(For example, you have had breast cancer first and then thyroid cancer)

- Yes
  - No
  - Unsure
- 

**13 If yes, what other type(s) of cancer did you have?**

- Bladder
  - Blood cancer/haematological (select one):
    - Hodgkin lymphoma
    - Diffuse B-cell lymphoma
    - Acute lymphocytic leukemia
    - Acute myelogenous leukemia
    - All other types of leukemia, non-Hodgkin lymphoma, myeloma
    - Not sure what type of blood cancer
- Brain/Central nervous system
- Breast
- Colorectal (colon or rectal cancer)
- Gynaecological (cervical, ovarian, uterine, or fallopian tube)
- Melanoma skin cancer (**not** basal cell carcinoma or squamous cell carcinoma)
- Prostate
- Sarcoma
- Stomach or esophagus
- Testicular
- Other (specify): \_\_\_\_\_

If you have been diagnosed with more than one type of cancer and are currently going through treatment (i.e., surgery, chemotherapy, radiation), please complete the remaining questions in this survey **about thyroid cancer**.

**14** In what year were you diagnosed with cancer?

Please remember to focus on your diagnosis of thyroid cancer

- Prior to 2010
- 2010
- 2011
- 2012
- 2013
- 2014
- 2015
- 2016
- 2017
- 2018
- 2019
- 2020

**15** Was this cancer diagnosed as metastatic, i.e., had the cancer spread to different parts of your body?

Example: thyroid cancer that has spread to lymph nodes or lungs

- Yes, it was diagnosed as metastatic
- No, it wasn't diagnosed as metastatic, but it spread afterwards
- No, it wasn't diagnosed as metastatic, and it did not spread
- Unsure

**16** What type(s) of cancer treatment did you receive for thyroid cancer, if any?

Please X all the boxes that apply to you

- Surgery
- Radioactive iodine (I-131) therapy
- Thyroid hormone replacement therapy
- Radiation therapy (external-beam radiation therapy)

**17** Other than thyroid hormone replacement therapy **when was the last time you received any type of thyroid cancer treatment in Question 16** (including surgery or radioiodine (I-131) therapy)

- |   |   |
|---|---|
| <input type="checkbox"/> Within the past six months         | <input type="checkbox"/> 3 to 5 years ago                     |
| <input type="checkbox"/> Six months to less than 1 year ago | <input type="checkbox"/> More than 5 years ago                |
| <input type="checkbox"/> 1 to 2 years ago                   | <input type="checkbox"/> I have not received cancer treatment |
| <input type="checkbox"/> 2 to 3 years ago                   |   |

**18** Are you currently receiving thyroid hormone replacement to prevent thyroid cancer from recurring?

e.g., Synthroid

- Yes (specify): \_\_\_\_\_  
 No  
 Unsure

**19** Did you participate in a cancer clinical trial (research study) at a cancer centre, cancer clinic or hospital for thyroid cancer?

- Yes  
 No  
 Unsure

### Health care providers who oversee your follow-up thyroid cancer care

As you know, this survey focuses on the time period after you completed your thyroid cancer treatment (e.g., surgery, radioactive iodine therapy, radiation therapy), otherwise known as follow-up cancer care.

Follow-up thyroid cancer care involves regular medical check-up, and your health care providers will check on your progress and help you deal with any concerns you may have. During follow-up thyroid cancer care, patients discuss with their health care providers any concerns they might be having which may include:

- **physical concerns** such as swelling, fatigue, hormonal changes, chronic pain, incontinence, nerve problems, sexual health and functioning, and changes to concentration.
- **emotional concerns** such as depression, anxiety, altered body image, and changes in relationships; and/or
- **practical concerns** like returning to work or school, getting to and from appointments, financial issues, and childcare or eldercare.

**20** Since completing your thyroid cancer treatment, which healthcare professional has been in charge of overseeing your follow-up cancer care?

- Family doctor/ general practitioner/ nurse practitioner  
 Your oncologist, endocrinologist, surgeon, or other cancer specialist  
 Both  
 No one  
 Unsure

**21** How involved is your family doctor/general practitioner/nurse practitioner in your follow-up thyroid cancer care?

- Very involved  
 Somewhat involved  
 Not very involved  
 Not at all involved  
 I do not have a family doctor/general practitioner/nurse practitioner  
 Unsure

**22** How much do you agree or disagree with the following statements about your family doctor/general practitioner/nurse practitioner when it comes to your follow-up thyroid cancer care?

Please X one box in each row

My family doctor/general practitioner/nurse practitioner...	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
... <b>understands</b> what I need when it comes to follow-up thyroid cancer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... <b>knows where to find</b> other supports and services to help in my follow-up thyroid cancer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...is <b>able to refer</b> me directly to other supports and services to help in my follow-up thyroid cancer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am <b>confident</b> that my family doctor/general practitioner/nurse practitioner <b>can take care of my needs</b> in follow-up thyroid cancer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**23** To the best of your memory, thinking about issues related to your follow-up thyroid cancer care, on average how many times per year did you visit or speak to each of the following?

Please X one box in each row

	5 or more times	3-4 times	1-2 times	Not at all	Don't remember	Not applicable
Family doctor/general practitioner/nurse practitioner/ Walk-in-clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your oncologist, endocrinologist, surgeon, or other cancer specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency rooms or urgent care centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

All survey responses will be kept strictly confidential. Your individual responses will never be shared with your health care team.

Overall experiences of follow-up thyroid cancer care

**24** Thinking about all the follow-up for thyroid cancer care services you received after you completed thyroid cancer treatment, how would you rate each of the following? Please consider all services you received in areas relating to your physical, emotional or practical needs.

Please X one box in each row

	Very good	Good	Fair	Poor	Very poor	Not applicable
Overall, receiving follow-up thyroid cancer care that met my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting the right services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting the right services when I needed them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receiving follow-up thyroid cancer care that was personalized to my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**25** How would you describe the overall care provided by each of the following after you completed thyroid cancer treatment?

Please X one box in each row

	Very good	Good	Fair	Poor	Very poor	Not applicable
Family doctor/general practitioner/nurse practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist, endocrinologist, surgeon, or other cancer specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**26** How much do you agree or disagree that you were able to visit or speak to your health care providers when you needed them after you completed thyroid cancer treatment?

Please X one box in each row

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
Family doctor/general practitioner/nurse practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist, endocrinologist, surgeon, or other cancer specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**27** How would you rate each of the following at being sensitive to your needs after you completed thyroid cancer treatment?

Please X one box in each row

	Very good	Good	Fair	Poor	Very poor	Not applicable
Family doctor/general practitioner/nurse practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist, endocrinologist, surgeon, or other cancer specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**28** How would you describe the usefulness of the thyroid cancer-related information provided to you by each of the following after you completed thyroid cancer treatment?

Please X one box in each row

	Very good	Good	Fair	Poor	Very poor	Not applicable
Family doctor/general practitioner/nurse practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist, endocrinologist, surgeon, or other cancer specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**29** How would you describe the communication between you and each of the following after you completed thyroid cancer treatment?

Please X one box in each row

	Very good	Good	Fair	Poor	Very poor	Not applicable
Family doctor/general practitioner/nurse practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist, endocrinologist, surgeon, or other cancer specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**30** How would you describe the coordination between your various doctors and health care providers when it comes to your follow-up thyroid cancer care (i.e., do they know what each other is doing)?

- |                                    |   |
|------------------------------------|---|
| <input type="checkbox"/> Very good | <input type="checkbox"/> Very poor      |
| <input type="checkbox"/> Good      | <input type="checkbox"/> Unsure         |
| <input type="checkbox"/> Fair      | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Poor      |   |

**31** In general, how much do you agree or disagree with the following statements about the information you were given after completing thyroid cancer treatment?

Please X one box in each row

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
Information was available to me when I needed it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given information that was useful to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given information in my preferred language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given information about signs of cancer returning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given information about the side effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given information about community resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**32** After completing your thyroid cancer treatment, was there a particularly challenging period(s) in terms of your ability to live your life the way you want to?

- Yes, 6 months to 1 year after
- Yes, 1 to 2 years after
- Yes, 2 to 3 years after
- Yes, more than 3 years after
- All periods were equally challenging
- There were no challenging periods
- Not applicable

**33** What was the main challenge you experienced after you completed thyroid cancer treatment?  
Please do not include any names or personal information in your response

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## Understanding the changes in different areas of your life

After completing thyroid cancer treatment, you may have experienced a variety of changes in the **physical, emotional or practical areas** of your life. These changes can vary from one person to the next and may become a concern for individuals.

We are interested in knowing **what types of changes you have faced**, as well as,

1) **How much each was a concern for you.** If it was a concern, we want to know...

2) **If you sought help for this concern.** If you did seek help,...

3) **How easy it was to get help?**

### Physical changes

Physical changes include a variety of things such as swelling, fatigue, hormonal changes, chronic pain, incontinence, nerve problems, sexual health and functioning, and changes to concentration, etc. Some of these changes may have become a concern for you.

	<b>34 How much was this a concern for you?</b>	<b>35 Did you seek help for this concern?</b>	<b>36 How easy was it to get help for this concern?</b>
<b>Swelling of arms or legs</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help
<b>Fatigue, tiredness</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help
<b>Menstrual concerns or fertility concerns</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help
<b>Chronic pain or long-term pain</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b> <input type="checkbox"/>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help

	<b>34 How much was this a concern for you?</b>	<b>35 Did you seek help for this concern?</b>	<b>36 How easy was it to get help for this concern?</b>
<b>Bladder and/or urinary problems (i.e., incontinence)</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help
<b>Gastrointestinal problems (i.e., constipation, diarrhea)</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help
<b>Nerve problems (numbness or tingling in the hands/ feet)</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help
<b>Changes to concentration, memory</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern... <b>Next item</b>	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next item</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help
<b>Changes in sexual activity or function</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern	<input type="checkbox"/> Yes → <input type="checkbox"/> No... <b>Next question</b>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Didn't get any help

**37** Please describe any other physical concerns you experienced.  
 Please do not include any names or personal information in your response

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**38** If you did not seek help with your physical concerns, which of the following best describes why not?

Please X all the boxes that apply to you

- I didn't want to ask
- I didn't know I could ask
- I didn't know where to go or who to ask
- I was embarrassed
- I didn't think there were services available to help me
- Someone told me it was normal to expect, and I didn't think anything could be done about it
- Other, please specify \_\_\_\_\_
- Not applicable – I didn't have any physical concerns... **Go to 41**

**39** If you sought help for your physical concern(s), which of these was the most difficult for you to get help for?

- Swelling of arms or legs
- Fatigue, tiredness
- Menstrual concerns or fertility concerns
- Chronic pain or long-term pain
- Bladder and/or urinary problems (i.e., incontinence)
- Gastrointestinal problems (digestion issues, bowel, incontinence)
- Nerve problems (numbness or tingling)
- Changes to concentration, memory
- Changes in sexual activity or function
- Other

**40** Thinking about the physical concern that was the most difficult to get help with, how long did it take for you to get help for this?

- Less than 3 months
- 3 to 6 months
- 6 to 9 months
- 9 to 12 months
- More than a year
- Was not able to get help

**41** Thinking only about your physical concerns during follow-up thyroid cancer care, how much do you agree or disagree with the following statements about your physical concerns?

Please X one box in each row

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
I received the care and support for my physical concerns when I needed it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I received useful information about my physical concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had to find information on my own about my physical concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family doctor/general practitioner/nurse practitioner was knowledgeable about my physical concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist/endocrinologist/surgeon/other specialist was knowledgeable about my physical concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital were knowledgeable about my physical concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital) were knowledgeable about my physical concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**42** In addition to your family doctor/general practitioner/nurse practitioner and thyroid cancer specialist, was there anyone else who helped or is helping you deal with your physical concerns?

Please X all the boxes that apply to you

- No, I am dealing with them myself
- Nurse navigator/pivot nurse/patient navigator (a 'go-to' person who can answer all your questions)
- Mental health specialist (e.g., psychiatrist, psychologist, therapist)
- Complementary or alternative practitioner (e.g., naturopath, traditional Chinese medicine practitioner, acupuncturist, massage therapist)
- Rehabilitation specialist (e.g., physiotherapist, speech therapist, occupational therapist, dietitian)
- Social worker
- Pharmacist
- Student services at my school or Employer's Employment Assistance Program (EAP)
- Religious, spiritual healer or cultural leader
- Non-profit organization
- Support group
- Online discussion forums
- Other (specify):  
\_\_\_\_\_

Not applicable... **Go to 44**

**43** Did you need to pay for any of these services to help you deal with your physical concerns?

- Yes, I paid out of my own pocket
- Yes, a family member or friend paid for it
- No, my private insurance covered it
- No, it was covered under government health insurance
- Not applicable
- Unsure

### Emotional changes

Emotional changes include a variety of things such as depression, anxiety, altered body image, and changes in relationships. Some of these changes may have become a concern for you.

	44 How much was this a concern for you?	45 Did you seek help for this concern?	46 How easy was it to get help for this concern?
Depression, sadness, loss of interest in everyday things	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
Anxiety, stress, worry about cancer returning	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
Changes in relationships with family, partners	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
Changes in relationships with friends or coworkers	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item <input type="checkbox"/>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
Changes in body image (i.e., confidence in appearance, etc.)	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
Changes in sexual intimacy	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next question	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help

**47** Please describe any other emotional concerns you experienced.  
Please do not include any names or personal information in your response

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**48** If you did not seek help with your emotional concern(s), which of the following best describes why you did not seek help?

Please X all the boxes that apply to you

- I didn't want to ask
- I didn't know I could ask
- I didn't know where to go
- I was embarrassed
- I didn't think there were services available to help me
- Someone told me it was normal to expect and I didn't think anything could be done about it
- Other, please specify \_\_\_\_\_
- Not applicable – I didn't have any emotional concerns ... **Go to 51**

**49** If you sought help for your emotional concern(s), which of these was the most difficult for you to get help for?

- Depression, sadness, loss of interest in everyday things
- Anxiety, stress, worry about cancer returning
- Changes in relationships with family, partners
- Changes in relationships with friends or coworkers
- Changes in body image (i.e., confidence in appearance, etc.)
- Changes in sexual intimacy
- Other

**50** Thinking about the emotional concern that was the most difficult to get help with, how long did it take for you to get help for this?

- Less than 3 months
- 3 to 6 months
- 6 to 9 months
- 9 to 12 months
- More than a year
- Was not able to get help

**51** Thinking only about your emotional concerns during follow-up thyroid cancer care, how much do you agree or disagree with the following statements about your emotional concerns?

Please X one box in each row

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
I received the care and support for my emotional concerns when I need it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I received useful information about my emotional concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had to find information on my own about my emotional concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist/ endocrinologist/other specialist was knowledgeable about my emotional concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family doctor/general practitioner/nurse practitioner was knowledgeable about my emotional concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital were knowledgeable about my emotional concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital) were knowledgeable about my emotional concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**52** In addition to your family doctor/general practitioner/nurse practitioner and endocrinologist/oncologist, was there anyone else who helped or is helping you deal with your emotional concerns?

Please X all the boxes that apply to you

- No, I am dealing with them myself
- Nurse navigator/pivot nurse/patient navigator (a 'go-to' person who can answer all your questions)
- Mental health specialist (e.g., psychiatrist, psychologist, therapist)
- Complementary or alternative practitioner (e.g., naturopath, traditional Chinese medicine practitioner, acupuncturist, massage therapist)
- Rehabilitation specialist (e.g., physiotherapist, speech therapist, occupational therapist, dietitian)
- Social worker
- Pharmacist
- Student services at my school or Employer's Employment Assistance Program (EAP)
- Religious, spiritual healer or cultural leader
- Non-profit organization
- Support group
- Online discussion forums
- Other (specify):

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Not applicable

**53** Did you need to pay for any of these services to help you deal with your emotional concerns?

- Yes, I paid out of my own pocket
- Yes, a family member or friend paid for it
- No, my private insurance covered it
- No, it was covered under government health insurance
- Not applicable
- Unsure

## Practical challenges

For this section, please disregard any challenges due to COVID-19 pandemic related restrictions.

Practical challenges include things like returning to work or school, getting to and from appointments, financial issues, and childcare or eldercare. Some of these changes may have become a concern for you.

	<b>54</b> How much was this a concern for you?	<b>55</b> Did you seek help for this concern?	<b>56</b> How easy was it to get help for this concern?
<b>Returning to (or future) work or school</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
<b>Getting to and from appointments</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
<b>Taking care of children, elders, or other family members</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
<b>Difficulty getting health or life insurance</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern...Next item	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next item <input type="checkbox"/>	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help
<b>Paying healthcare bills (e.g., treatment, services, travel to appointments, assistive devices)</b>	<input type="checkbox"/> Big → <input type="checkbox"/> Moderate → <input type="checkbox"/> Small → <input type="checkbox"/> Not a concern	<input type="checkbox"/> Yes → <input type="checkbox"/> No...Next question	<input type="checkbox"/> Very easy <input type="checkbox"/> Easy <input type="checkbox"/> Hard <input type="checkbox"/> Very hard <input type="checkbox"/> Did not get any help

**57** Please describe any other practical challenges you experienced.  
Please do not include any names or personal information in your response

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**58** If you did not seek help with your practical challenges, which of the following best describes why you did not seek help?

Please X all the boxes that apply to you

- I didn't want to ask
- I didn't know I could ask
- I didn't know where to go
- I was embarrassed
- I didn't think there were services available to help me
- Someone told me it was normal to expect, and I didn't think anything could be done about it
- Other, please specify \_\_\_\_\_
- Not applicable – I didn't have any practical concerns, or I sought help

**59** If you sought help for your practical challenges, which of these was the most difficult for you to get help for?

- Returning to (or future) work or school
- Getting to and from appointments
- Taking care of children, elders, or other family members
- Difficulty getting health or life insurance
- Paying health care bills (e.g., treatment, services, travel to appointments, assistive devices)
- Other

**60** Thinking about your practical challenges that was most difficult to get help with, how long did it take for you to get help for this?

- Less than 3 months
- 3 to 6 months
- 6 to 9 months
- 9 to 12 months
- More than a year
- Was not able to get help
- Not applicable

**61** Thinking only about your practical challenges during follow-up thyroid cancer care, how much do you agree or disagree with the following statements about your practical concerns?

Please X one box in each row

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
I received the care and support for my practical challenges when I need it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I received useful information about my practical challenges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had to find information on my own about my practical challenges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My oncologist/endocrinologist/surgeon/other specialist was knowledgeable about my practical challenges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family doctor/general practitioner/nurse practitioner was knowledgeable about my practical challenges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the cancer centre, cancer clinic or cancer program in a hospital were knowledgeable about my practical challenges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health care providers in the community (i.e., not in a cancer centre/cancer clinic/hospital) were knowledgeable about my practical challenges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**62** In addition to your family doctor/general practitioner/nurse practitioner and endocrinologist/oncologist, was there anyone else who helped or is helping you deal with your practical concerns?

Please X all the boxes that apply to you

- No, I am dealing with them myself
- Nurse navigator/pivot nurse/patient navigator (a 'go-to' person who can answer all your questions)
- Mental health specialist (e.g., psychiatrist, psychologist, therapist)
- Complementary or alternative practitioner (e.g., naturopath, traditional Chinese medicine practitioner, acupuncturist, massage therapist)
- Rehabilitation specialist (e.g., physiotherapist, speech therapist, occupational therapist, dietitian)
- Social worker
- Pharmacist
- Student services at my school or Employer's Employment Assistance Program (EAP)
- Religious, spiritual healer or cultural leader
- Non-profit organization
- Support group
- Online discussion forums
- Other (specify):

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Not applicable

**63** Did you need to pay for any of these services to help you deal with your practical concerns?

- Yes, I paid out of my own pocket
- Yes, a family member or friend paid for it
- No, my private insurance covered it
- No, it was covered under government health insurance
- Not applicable
- Unsure

**64** Below is a list of ways a thyroid cancer patient can get support or counselling during the first few years of follow-up thyroid cancer care. Please indicate which of the following best describes your experience with the type of support or counselling in each row

	Participated and liked it	Participated but didn't like it	Didn't participate	Never heard of this
One-on-one counselling with a support therapist, psychologist, social worker, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One-on-one peer mentorship program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A professionally led online peer support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Face-to-face peer support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone peer support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ongoing online peer support through social media, such as a Facebook group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wellness program in your community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group retreat weekends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**65** After your thyroid cancer treatment, did you have someone close to you, such as a friend or family member, who helped provide support for your follow-up thyroid cancer care needs (emotional, physical or practical needs)?

Please X all the boxes that apply to you

- Yes, members of my immediate family (spouse, parents, children)
- Yes, members of my extended family
- Yes, friends
- Other
- No

**66** Reflecting on your experience with follow-up care after completing thyroid cancer treatment, please describe any ONE (1) positive experience you may have had that you think would benefit others going through a similar situation.  
Please do not include any names or personal information in your response

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**67** Overall, what were the TWO (2) most important things that could have been done, that were not done, to help you effectively deal with your needs after thyroid cancer treatment?

Please do not include any names or personal information in your response

1. \_\_\_\_\_

\_\_\_\_\_

2. \_\_\_\_\_

\_\_\_\_\_

#### Access to follow-up cancer care plans and medical records

**68** Did you receive a formal written plan for your follow-up thyroid cancer care from the cancer centre/clinic/hospital where you received cancer treatment?

A plan for follow-up thyroid cancer care is shared with your family doctor/general practitioner/nurse practitioner. The plan is **specific to your needs** after treatment for thyroid cancer has ended, and includes information about what to expect, which doctor to see, when and how often follow-up tests should be done

- Yes, I got a plan BEFORE I completed cancer treatment
- Yes, I got a plan AFTER I completed cancer treatment
- No, I heard about a plan but never got one
- No, I never heard of a plan
- Not applicable

**69** After completing thyroid cancer treatment, did you see or get a copy of your medical records, charts, prescription history, etc. when you wanted to?

- Yes, I had access
- Yes, I had access, but I wasn't interested
- Yes, I had access, but didn't want to pay for it
- No, I didn't know I could have access
- Not applicable

**70** How important is it to you to be able to see or get copies of all your medical information?

- Very important
- Somewhat important
- Not very important
- Not at all important

## Health insurance

**71** What type of health insurance coverage did you have after your thyroid cancer treatment was completed?

Please X all the boxes that apply to you

- A government-sponsored plan, such as Drug Benefit for those over 65, or disability benefits
- My employer-sponsored benefit plan
- My spouse's or my parent's employer-sponsored benefit plan
- A plan sponsored through an association such as a union, trade association, or through my post-secondary institution
- Other, such as my own private plan purchased from an insurance company
- I do not have an insurance plan
- Not applicable

**72** To what extent do you agree or disagree with the statements below about your insurance coverage after thyroid cancer treatment?

Please X one box in each row

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
I knew about my insurance options after completing thyroid cancer treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I experienced difficulty getting insurance coverage for my needs after completing thyroid cancer treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My insurance coverage covered most of my follow-up thyroid cancer care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Just a few more questions

In this section, we ask a set of questions to determine if different types of patients report their experiences in different ways. We are also asking these questions to ensure we are hearing from a variety of individuals.

### 73 Were you born in Canada?

- Yes.....Go to 75
- No
- Prefer not to answer..... Go to 75

### 74 When did you move to Canada?

- Less than 5 years ago
- 5 to 10 years ago
- More than 10 years ago
- Prefer not to answer

### 75 What language(s) do you speak most often at home?

Please X all the boxes that apply to you

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> English                | <input type="checkbox"/> Italian         | <input type="checkbox"/> Spanish               |
| <input type="checkbox"/> French                 | <input type="checkbox"/> Korean          | <input type="checkbox"/> Tagalog               |
| <input type="checkbox"/> An Aboriginal language | <input type="checkbox"/> Persian (Farsi) | <input type="checkbox"/> Tamil                 |
| <input type="checkbox"/> Arabic                 | <input type="checkbox"/> Polish          | <input type="checkbox"/> Urdu                  |
| <input type="checkbox"/> Chinese/Cantonese      | <input type="checkbox"/> Portuguese      | <input type="checkbox"/> Vietnamese            |
| <input type="checkbox"/> Chinese/Mandarin       | <input type="checkbox"/> Punjabi         | <input type="checkbox"/> Other, specify: _____ |
| <input type="checkbox"/> German                 | <input type="checkbox"/> Russian         | <input type="checkbox"/> Prefer not to answer  |

### 76 What is your highest level of education?

- Grade school or less
- Some high school
- High school diploma or certificate
- Some college or technical school/CEGEP
- College or technical school/CEGEP
- Some university
- University undergraduate degree (Bachelor's)
- University graduate degree (Master's or PhD)
- Prefer not to answer

### 77 Do you currently live in the same location as you did when you were getting treatment for thyroid cancer?

- Yes
- No
- Prefer not to answer

### 78 Which of the following best describes where you currently live?

- On an acreage, ranch or farm
- In a town (less than 2,000 people)
- In a town (2,000 - 10,000 people)
- In a small city (10,000 - 50,000 people)
- In a large city (more than 50,000 people)

**79** Which **ONE** of the following best describes your current employment situation?

- Working full-time
- Working part-time
- On vacation or paid leave
- On paid sick leave/disability leave due to cancer
- On paid sick leave/disability leave due to other reason
- I am a homemaker/stay-at-home parent
- I am a full-time student
- I am retired
- I am currently unemployed
- Prefer not to answer

**80** What is your total annual household income **before taxes**?

If you are a student and your health care needs are financially supported by your parents, please indicate your parents' total annual household income before taxes

- Less than \$25,000
- \$25,000 to less than \$50,000
- \$50,000 to less than \$75,000
- \$75,000 to less than \$125,000
- \$125,000 or more
- Prefer not to answer

**Internet use**

**81** How often do you do each of the following?

Please X one box in each row

	Every day	2-3 times a week	Once a week	Once every two weeks	Once a month or less	Never
Use the internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use social networking sites on the internet (Facebook, Twitter, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**82** When it comes to thyroid cancer-related issues or topics, which of the following, if any, have you done on social media or websites?

Please X all the boxes that apply to you

- Written about my own opinions
- Commented on what others have written
- Shared links to articles or information
- Read what others have posted
- Clicked on health-related posts/videos
- None of the above

## Thyroid Hormone Replacement

**83** What form of thyroid hormone replacement you are taking?

Please X all the boxes that apply to you

- T4 (Such as Synthroid, Levothyroxine or similar)
  - o If other, please specify: \_\_\_\_\_
- T3 (Such as Cytomel)
  - o If other, please specify: \_\_\_\_\_
- Any other form of thyroid hormone replacement (e.g., Armor, desiccated thyroid)
  - o If other, please specify: \_\_\_\_\_

**84** Have you been told by your healthcare team that your current level of thyroid hormone replacement is adequate for your specific requirements?

- Yes
- No
- Unsure

**85** Do you feel that you have current emotional and/ or physical changes because of inadequate thyroid hormone replacement? (If "no" or "prefer not to answer, end survey here).

- Yes
- No
- Unsure

**86** If you answered yes to the above, what current emotional and/ or physical changes do you feel you have because of inadequate thyroid hormone replacement?

Please do not include any names or personal information in your response

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**87** A follow up study is being planned for thyroid cancer specific survivorship issues. If you are interested in being involved, then please select Yes

- Yes
- No

Final Comments from you

**88** Do you have any final comments that you would like to share to help improve the follow up care for patients after thyroid cancer treatment ends

Please do not include any names or personal information in your response

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Thank you for completing this survey. Your responses are very valuable to helping make changes to improve the health care system.