

The logo for YACC (Young Adult Cancer Canada) features the word "yacc" in a bold, blue, lowercase sans-serif font. It is contained within a white speech bubble with a yellow border and a small tail pointing downwards and to the left.

yacc

young adult cancer canada

Intro to YACC

Young adults with cancer

Adolescents & Young Adults are cancer's "forgotten generation", i.e. Generation F.



The AYA National Network in Canada and the National Cancer Institute (NCI) in the USA define adolescent young adult (AYA) as 15-39 years of age.

There are over 8,300 AYA diagnosed with cancer in Canada annually.

An estimated 50,000-320,000 "survivors" living with or beyond their diagnosis.

Generation F. – What does it mean?



Lowest survival improvement

Lowest participation in clinical trials

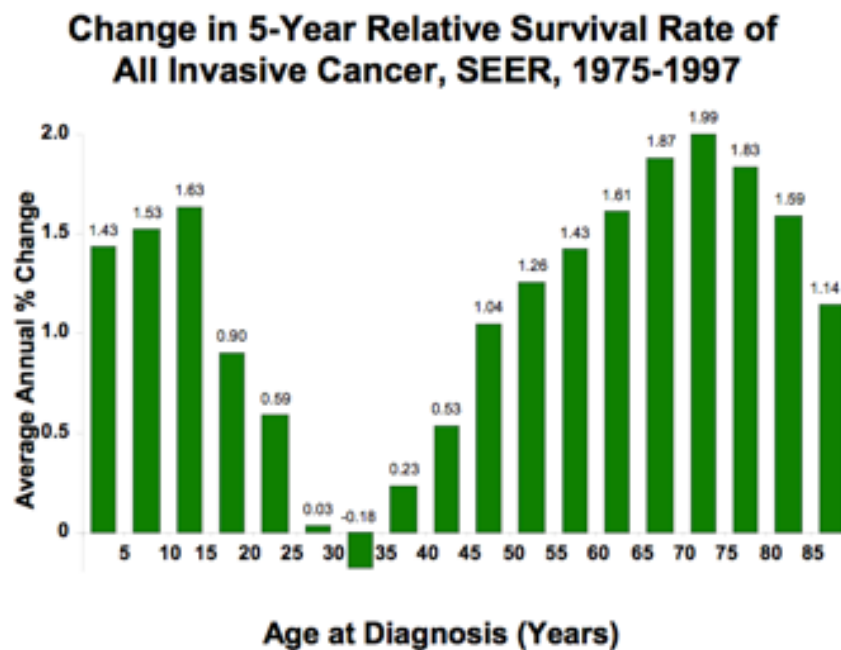
Next to no research agenda

Long term Survivorship

Next to no local support

Next to no community resources

Generation F. – Survival Improvement



Generation F. – Lost potential



TABLE 1 **PYLL* vs. CANCER INCIDENCE FOR VARIOUS AGE GROUPS** – 2002 DATA

AGE RANGE	PYLL	% OF TOTAL PYLL	INCIDENCE	INCIDENCE %
0-14 years	56,000	6.0%	845	1.1%
15-39 years	263,000	28.3%	6,817	9.1%
40-69 years	610,000	65.7%	66,930	89.8%
TOTAL	929,000		74,592	100 %

***PYLL** Potential Years of Life Lost

Generation F. – Survivorship

AYA survival rate is ~80%+ in Canada.



Save the kids, we will live with the impact of cancer longer than any other age group.

Thus there is an increased need for holistic Survivorship care.

Generation F. – Clinical Trials



“The AYA age group has the lowest proportion of patients with cancer entered in clinical trials...”

– Dr. Archie Bleyer

Generation F. – Research

No national or international research efforts.



A 2017 report from the Canadian Partnership Against Cancer found 0.4% of cancer research spending in Canada is focused on adolescents and young adults.

0.4%

Generation F. – Local Support

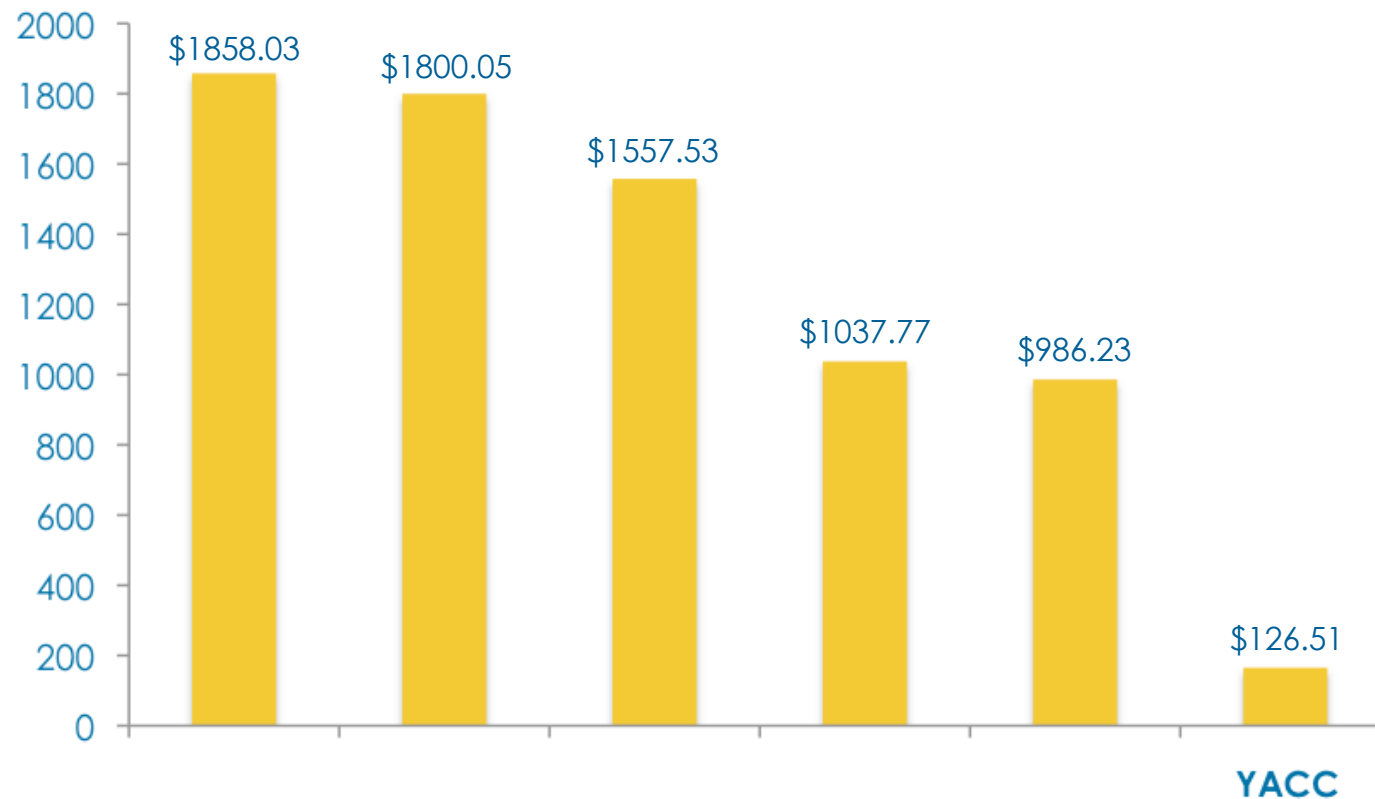


3-11

**The number of local support groups in
Canada... it changes constantly.**

Community resources??

Funds raised per diagnosis



Why YACC?

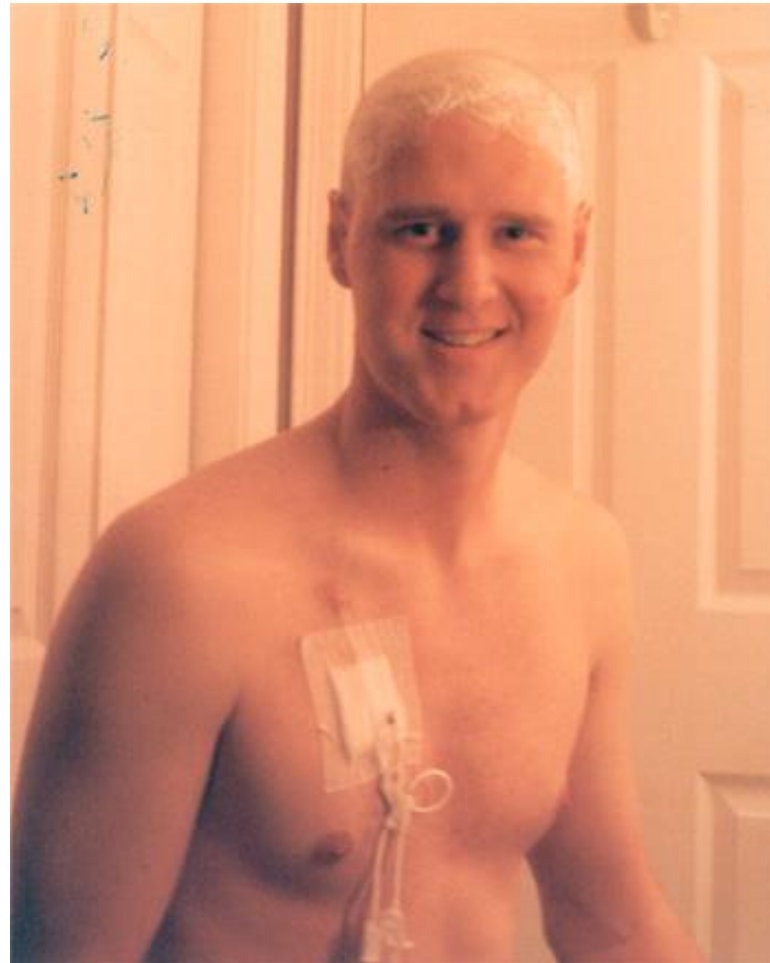
Cancer is different for young adults.



And...

It takes longer to recover from cancer than to be treated for it.

Cancer is different



Cancer is different: Isolation



*YACCers like Dani,
diagnosed with colon
cancer at 23, she says...*

*“the isolation was one of
the only side effects I
couldn’t take a pill for,
and it also lingered the
longest. The retreat was
hands down the most
important experience of
my life.”*



How YACC works

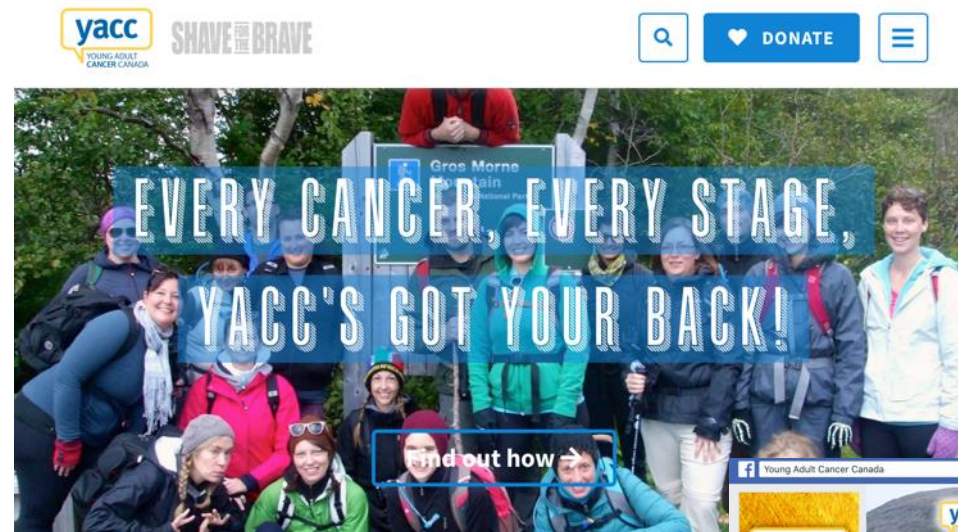


**To support young adults with, through
and beyond cancer.**

**Our support starts with connection...
web, local and national connections.**

**“Every cancer, every stage, YACC’s
got your back.”**

Web connections 24/7



Our Programs – Face to Face

Local Programs



Casual, social, fun in
eight cities across
Canada



Our Programs – Face to Face

4-Day Programs



yacc

SURVIVOR CONFERENCE

#CrushCancer

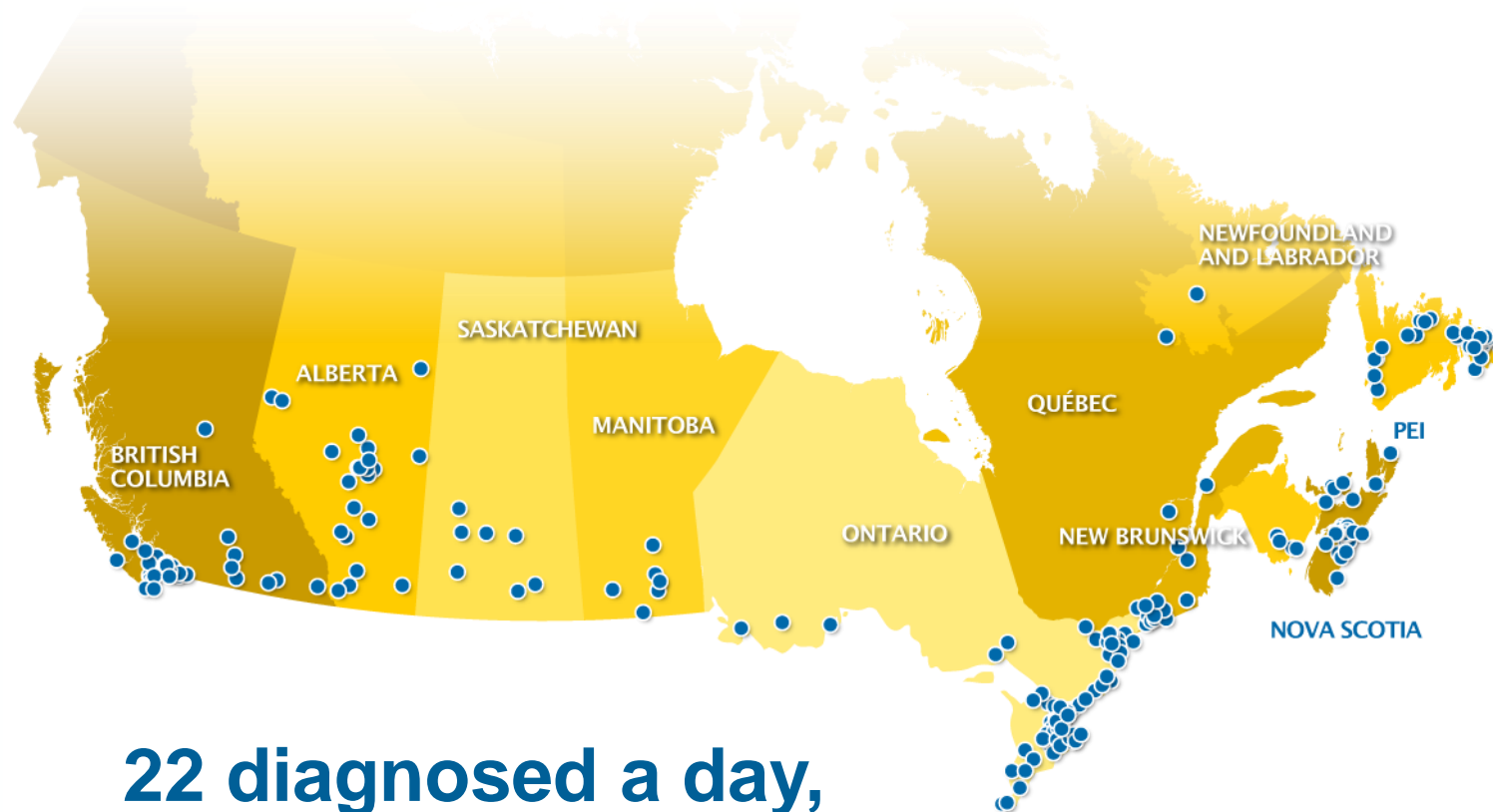
yacc

YOUNG ADULT
CANCER CANADA



Every cancer, every stage, YACC's got your back.

YACC's Survivor Community of 2800 young adults.



**22 diagnosed a day,
1 finds YACC**

The Financial Impact of Cancer in Young Adults

A Young Adults with Cancer in their Prime (YACPRIME) Study



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Assistant Professor, Department of Psychology
Cross-Appointed to the Discipline of Oncology



Why the Financial Impact of Cancer is Different for YAs

- Due to their age, most YAs lack parental support but have not yet established substantial personal savings.
- Personal responsibilities, such as student loan payments, mortgage payments, and childcare costs make young adulthood a financially taxing developmental period.
- The financial impact of cancer can take various forms, ranging from emptying savings accounts and other assets, accruing credit card debt, or declaring bankruptcy.
- As a result, the financial impact of cancer can be disproportionately greater for YAs than other age groups.

Why the Financial Impact of Cancer is Different for YAs

- The financial impact of cancer may present differently whether the individual is an emerging adult (age 20 to 25) or young adult (age 26 to 39). (Salsman et al. *Pediatric blood & cancer*, 2019)
- Emerging adults are transitioning towards independence, and thus are more likely to suffer the financial ramifications of disrupting their education.
- YAs 30 and older are more likely than emerging adults to have established a career, own a home, be in a committed relationship and have children. Consequently, these individuals are most affected by an inability to return to work in order to maintain earnings.

Why the Financial Impact of Cancer is Different for YAs

- US literature has found that YAs with cancer:
 - Have **lower** median income, **greater** out of pocket expenses and **lower** net worth than YAs of similar age (Landwehr et al., *Cancer Medicine*. 2016)
 - Have **more** educational disruption, and a **loss** of financial independence (Xiao et al., *International Journal of Consumer Studies* 2014)
- Need to explore in a Canadian context
 - Differences in healthcare systems

What Do We Know Already?... Not Much!

- A retrospective cohort study out of British Columbia examined the impact of a cancer diagnosis on later income in 4,027 childhood, adolescent and YA cancer survivors up to age 25 compared to age and sex matched peers (Teckle et al., *BMC Health Serv Res.* 2018)
 - 66% of the sample having been diagnosed between 15 and 24 years of age .
- Using a mean follow up time of 16 years
 - Cancer survivors earned significantly less than age and sex matched peers.
 - Survivors who relapsed also tended to earn significantly less than those who did not relapse.
- This study did not include those diagnosed past age 24

Objectives

- **Aim 1**
 - To assess the impact of current age on financial well-being
 - Comparing those individuals currently < 34 years to individuals > 35 years to determine whether individuals diagnosed with cancer in young adulthood financially recover in older adulthood.
- **Aim 2**
 - To assess the impact of time since diagnosis on financial well-being
 - Comparing those individuals within 5 years of their diagnosis to those greater than 5 years to determine whether greater time since diagnosis is associated with better financial well-being in YAs.
- **Aim 3**
 - To determine how out of pocket expenses and time off work contribute to this financial impact

Young Adults with Cancer in their Prime (YACPRIME)

- **What is YACPRIME?**
 - Online cross sectional survey of YAs conducted in collaboration with Young Adult Cancer Canada (YACC)
- **Eligibility Criteria**
 - Diagnosed with **any type** or **stage** of cancer between ages 15 and 39
 - Currently 19 years old or older
 - Bilingual survey open to English and French speaking Canadians

Methods

- The financial questions were taken directly from the 2014 Canadian Financial Capability Survey (CFCFS)
- The CFCFS is a national Statistics Canada survey that provides a benchmark of how Canadians fare on a number of financial well-being indicators

Methods

- Raw data for personal income was not available in the CFCS.
- Personal income question was taken directly from the 2014 Canadian Community Health Survey (CCHS).
- The CCHS is an annual cross-sectional survey conducted by Statistics Canada with the objective of gathering information related to health determinants for the Canadian population, including personal income.

Income

- Which of the following categories best describes your personal income?
 - 1: Less than \$20,000
 - 2: \$20,000 to less than \$40,000
 - 3: \$40,000 to less than \$60,000
 - 4: \$60,000 to less than \$80,000
 - 5: \$80,000 to less than \$100,000
 - 6: \$100,000 or more

Debts and Liabilities

- Do you have any of the following types of debts/liabilities?
 - Mortgages
 - Student loans
 - Payday loans
 - Other loans
 - Outstanding credit card balance
 - Outstanding line of credit balance
- What is the total value of these debts/liabilities?
 - Less than \$50,000
 - \$50,000 to \$99,999
 - \$100,000 to \$149,999
 - \$150,000 to \$199,999
 - \$200,000 to \$249,999
 - \$250,000 or more

Assets

- Do you own any of the following types of assets?
 - House or property
 - Vehicles
 - Collections, antiques, jewels and other valuables
 - None
 - Other
- What is the total value of these assets?
 - Less than \$100,000
 - \$100,000 to less than \$200,000
 - \$200,000 to less than \$300,000
 - \$300,000 to less than \$500,000
 - \$500,000 or more

Out of Pocket Expenses and Missed Work

- How much money do you estimate you currently spend out of pocket per month on cancer-related expenses?
e.g. hospital parking, medications not covered by insurance, costs for other treatment providers, travel and accommodations, etc.
 - Less than \$100
 - \$100-\$250
 - \$250-\$500
 - \$500-\$1000
 - \$1000 or more
- How much work have you missed because of your cancer diagnosis and/or treatment?
 - Less than 30 days
 - 30 days to less than 180 days
 - 180 days to less than 365 days
 - 365 days to less than 1095 days
 - 1095 days or more

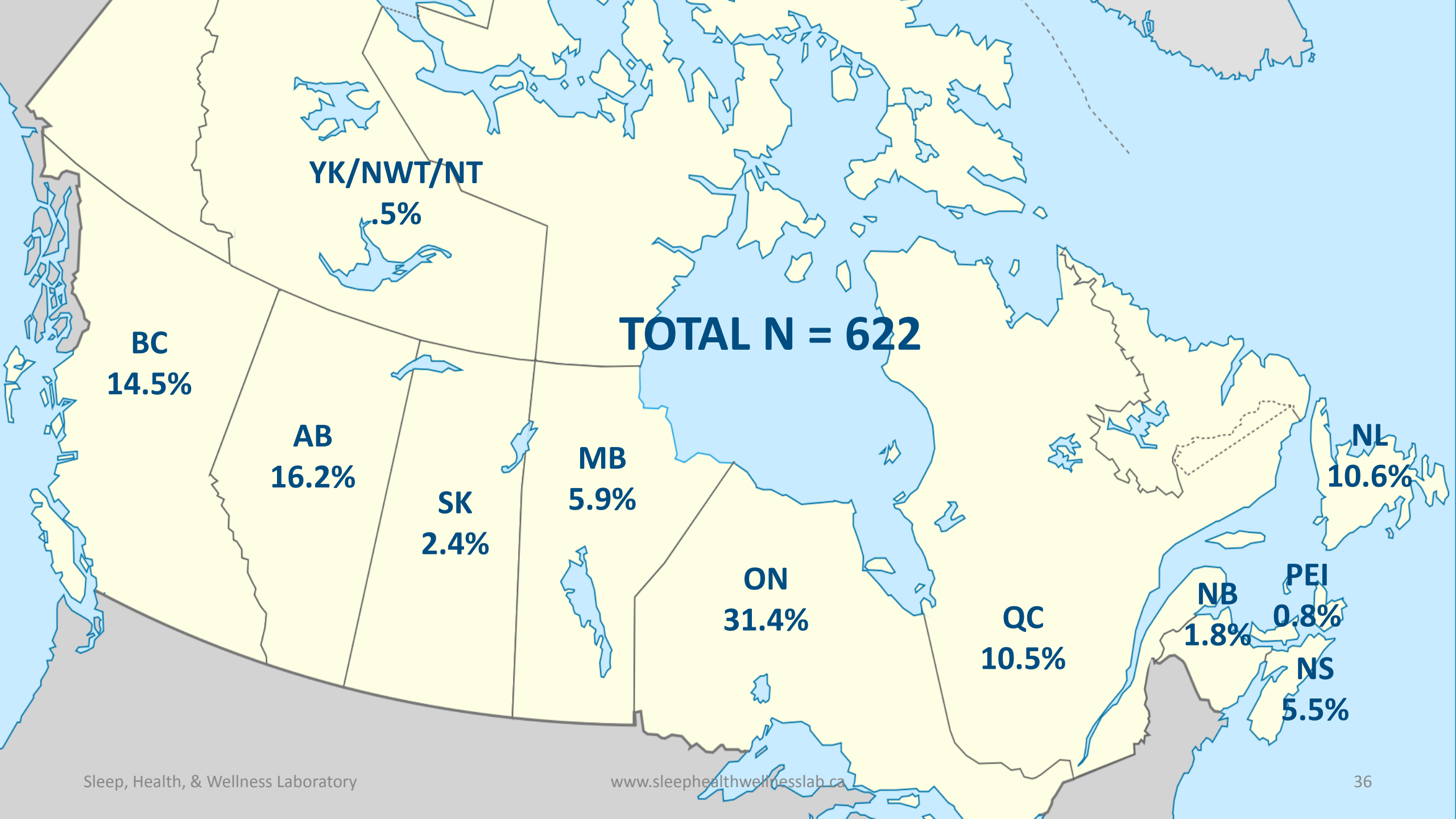
Analysis

- Case matching was used in order to create a comparison sample for each of the analyses.
- The YACPRIME sample was first separated to determine the frequencies of age group, sex, and education status. This was constrained by the categories offered in the CFCS and CCHS surveys.
- Using these frequencies, cases from the CFCS and CCHS were randomly sampled for all age, sex and education frequencies in order to create a comparison group consisting of YAs without cancer.
- Once controls were randomly selected, CFCS controls and CCHS controls were separately merged with the YACPRIME dataset to allow for direct comparison between YAs with and without cancer.

Analysis

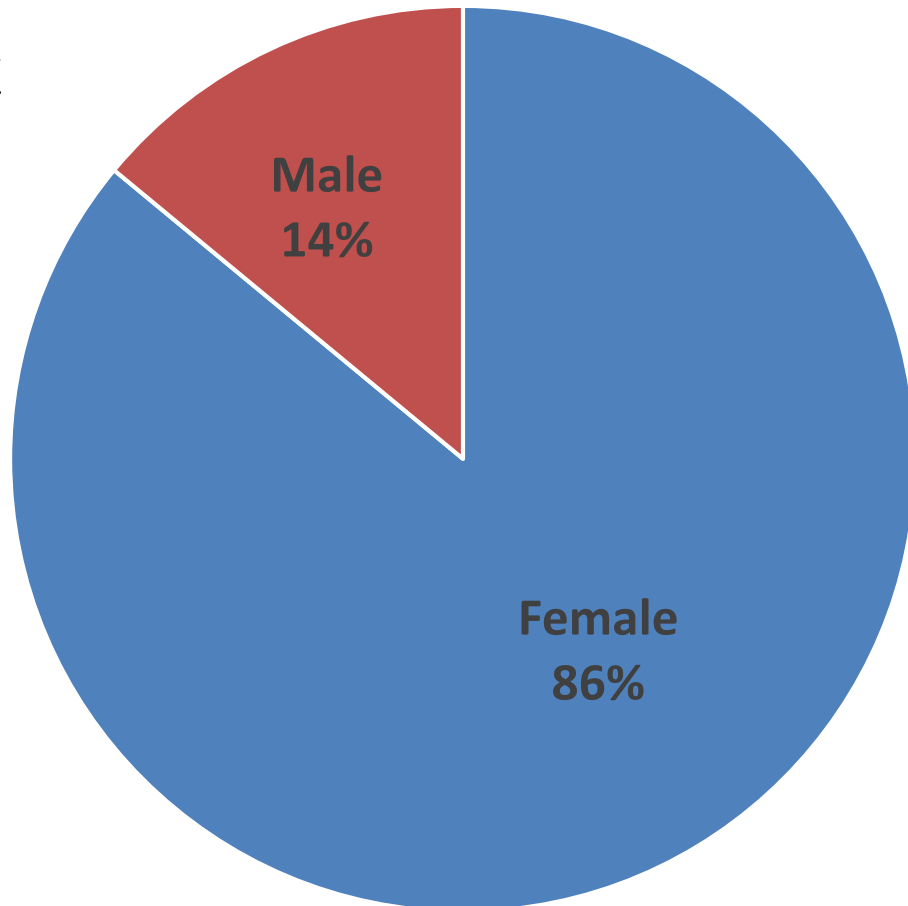
- For all analyses, chi square tests of associations were used to compare YAs with cancer to their non-cancer peers.
- The criterion used was $p \leq .05$.
- Odds ratios were also calculated for any significant findings.

Who is YACPRIME?

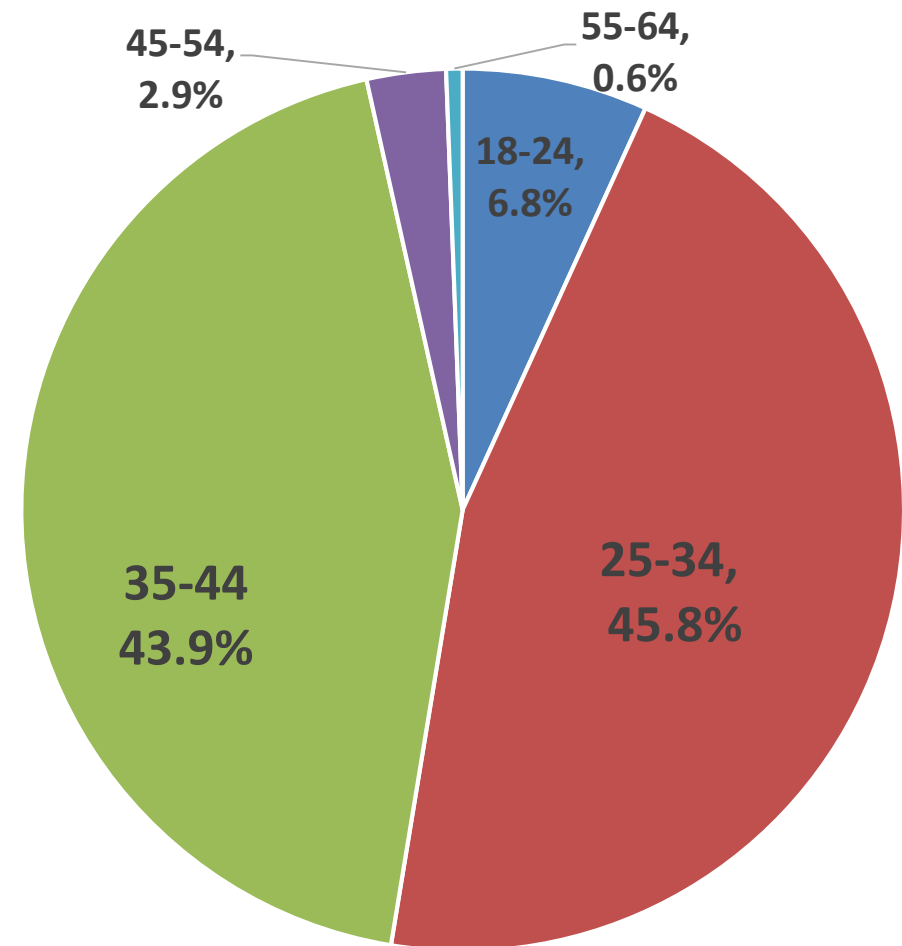


Sex and Age

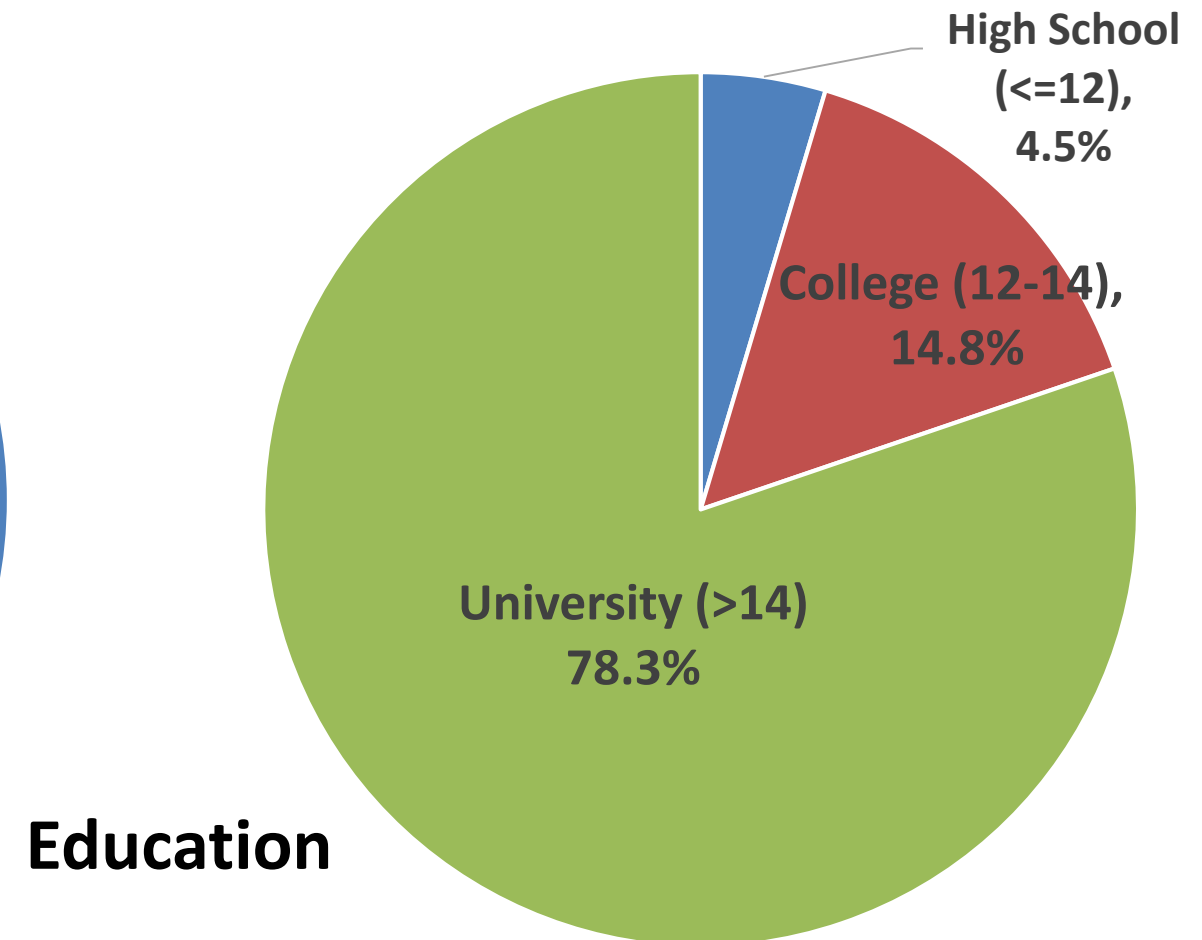
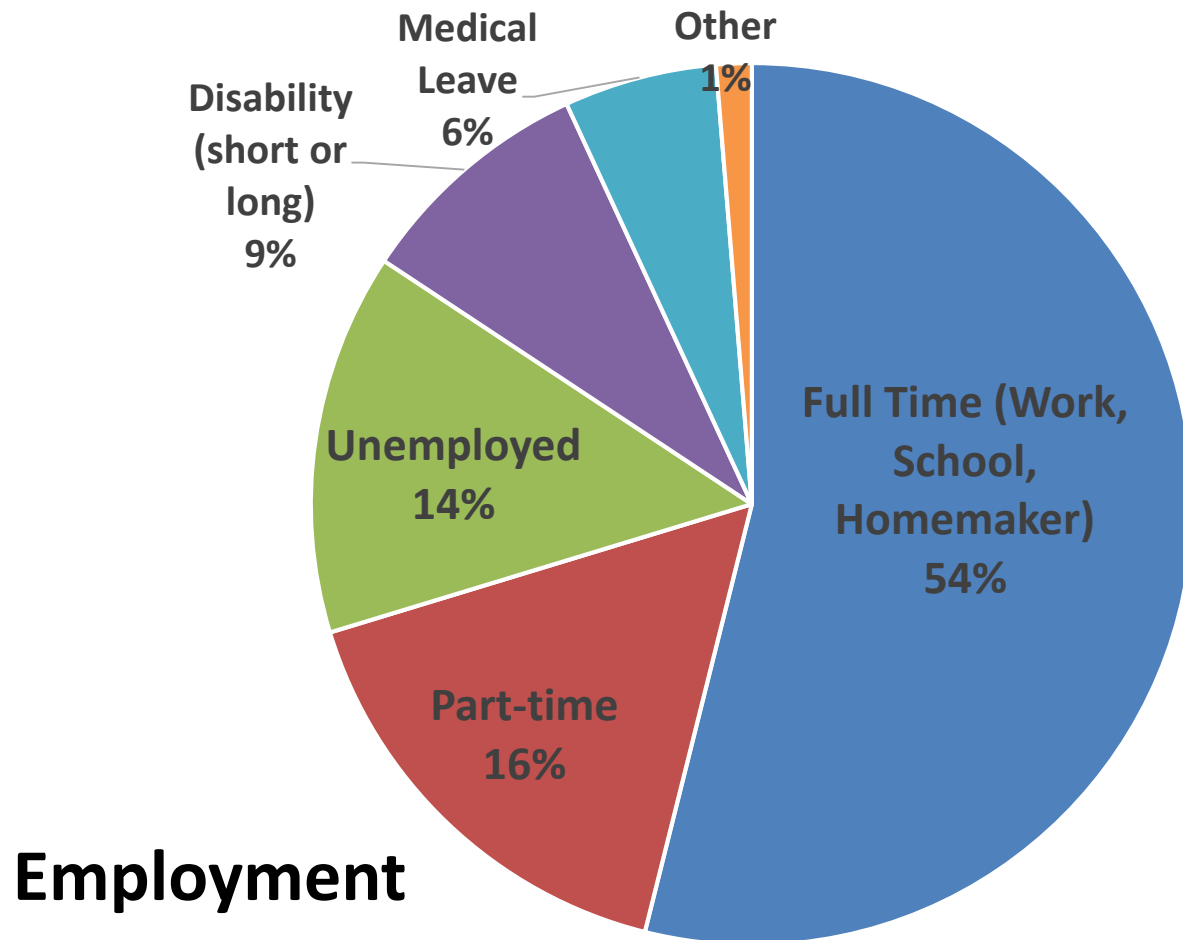
Sex



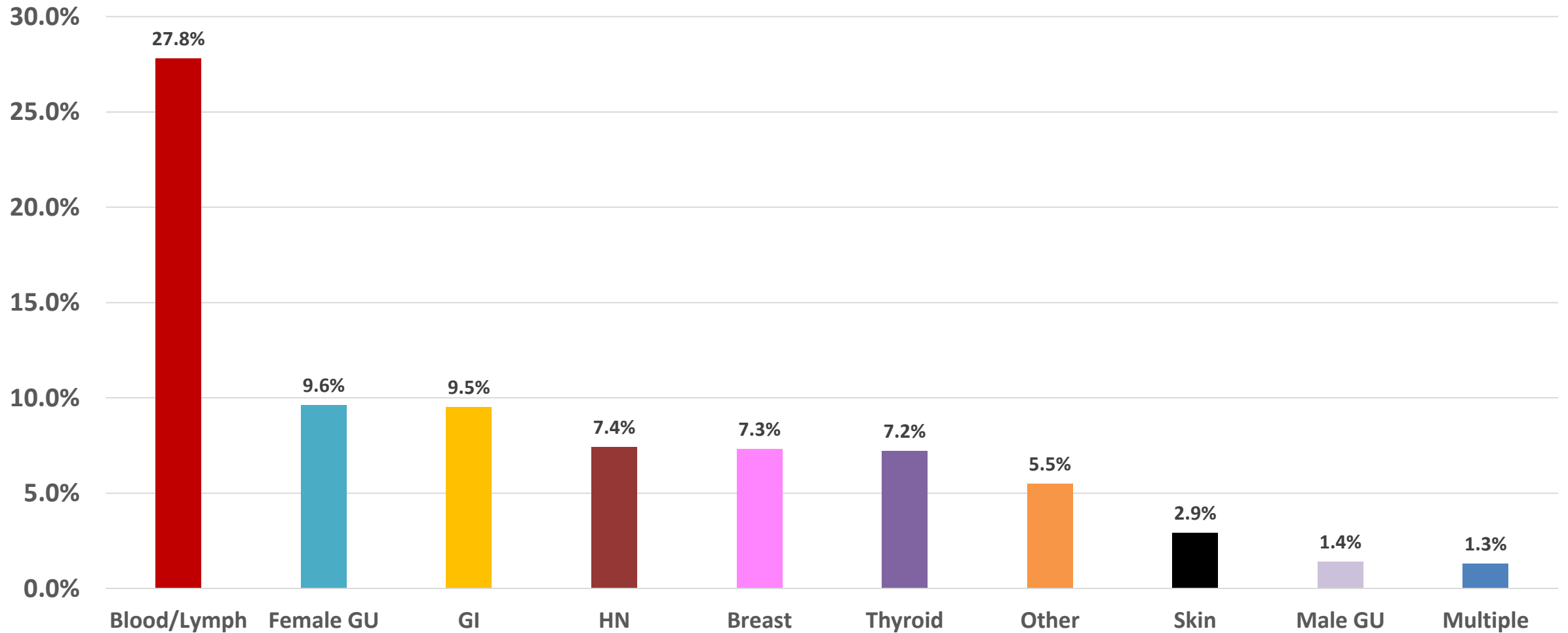
Age



Employment Status and Education

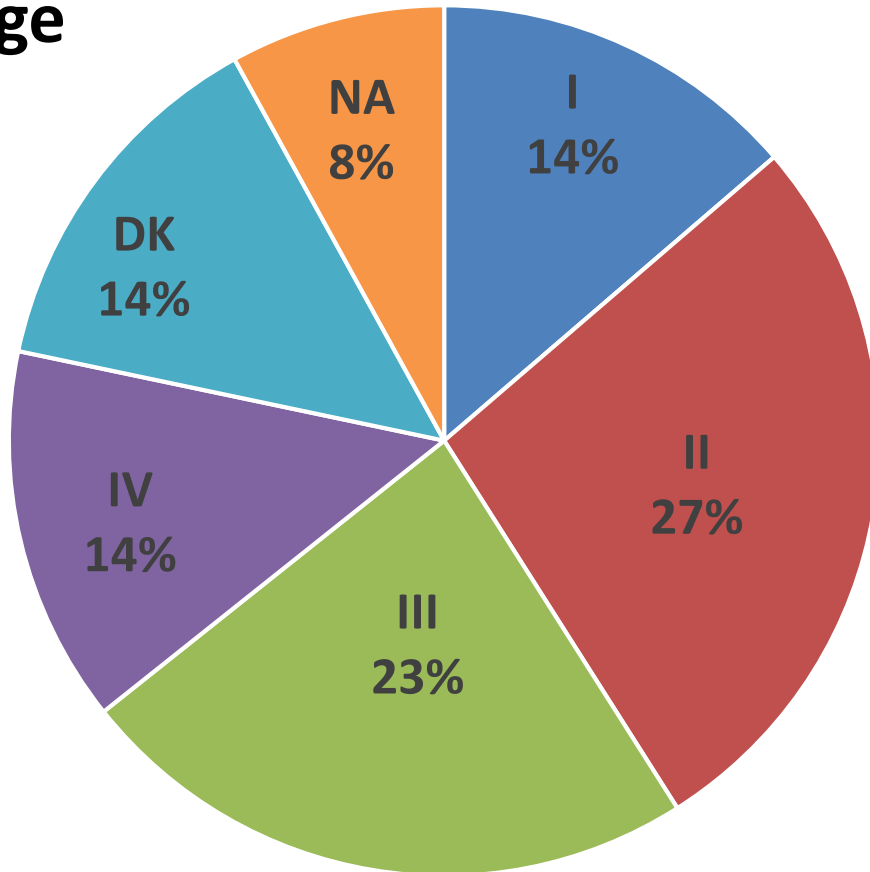


Cancer Type

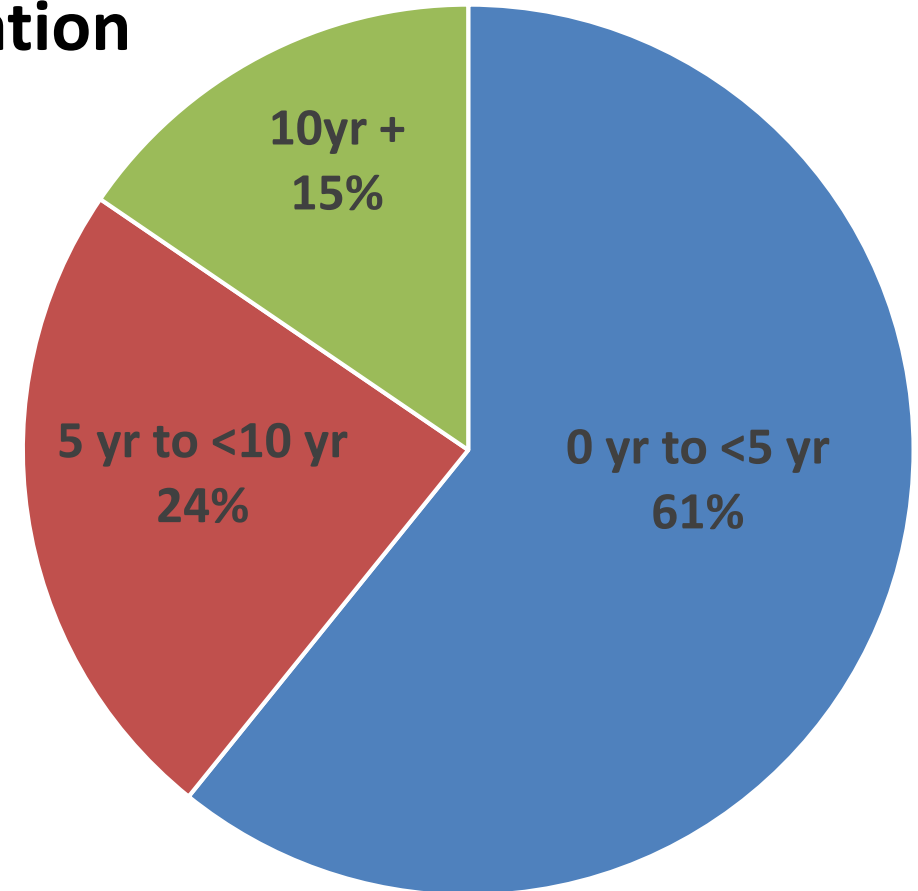


Stage of Disease and Duration

Stage

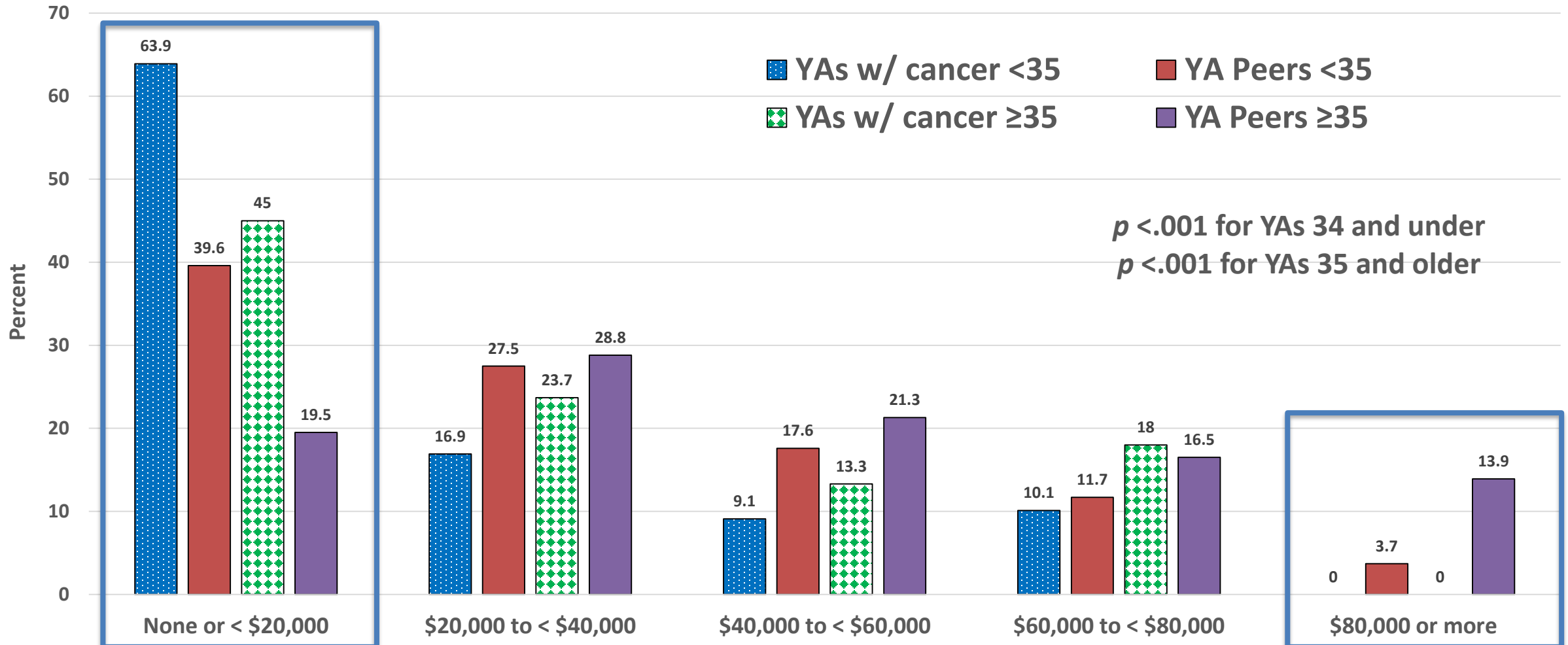


Duration

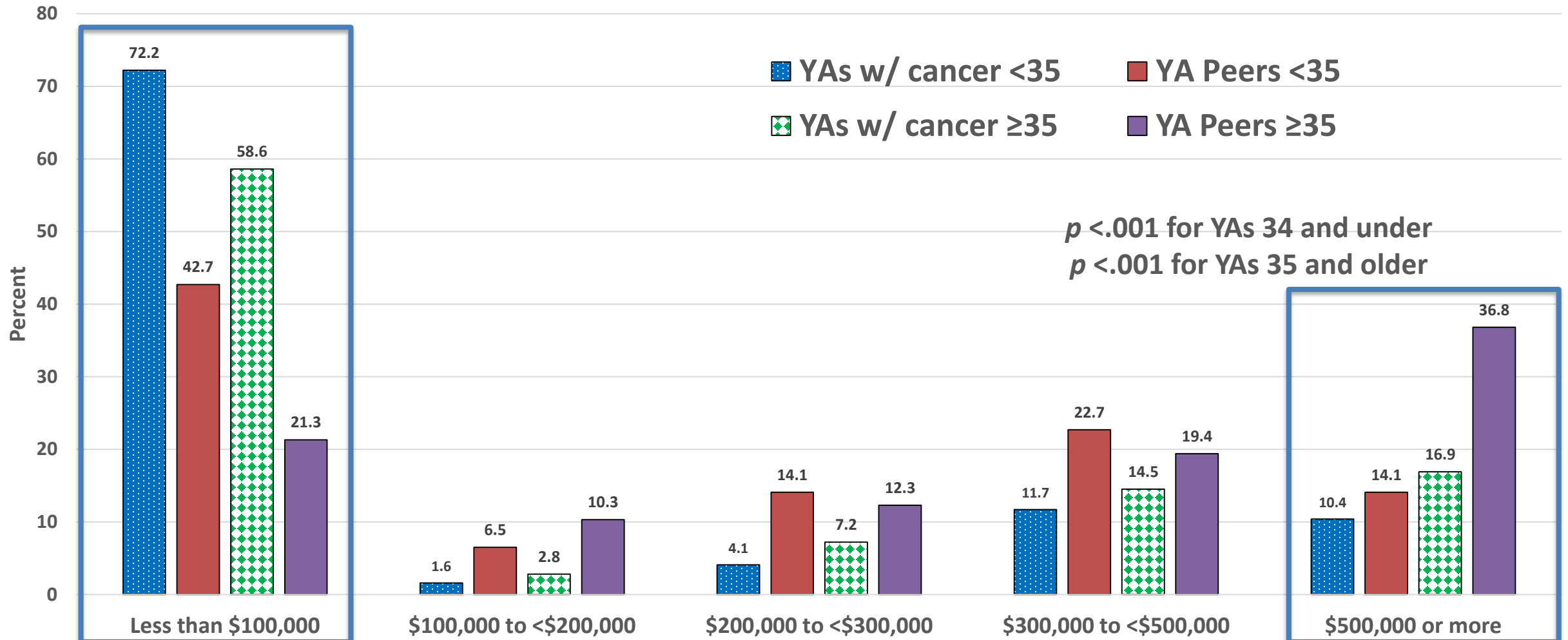


Do YAs With Cancer Recover Financially As They Age?

Personal Income by Current Age



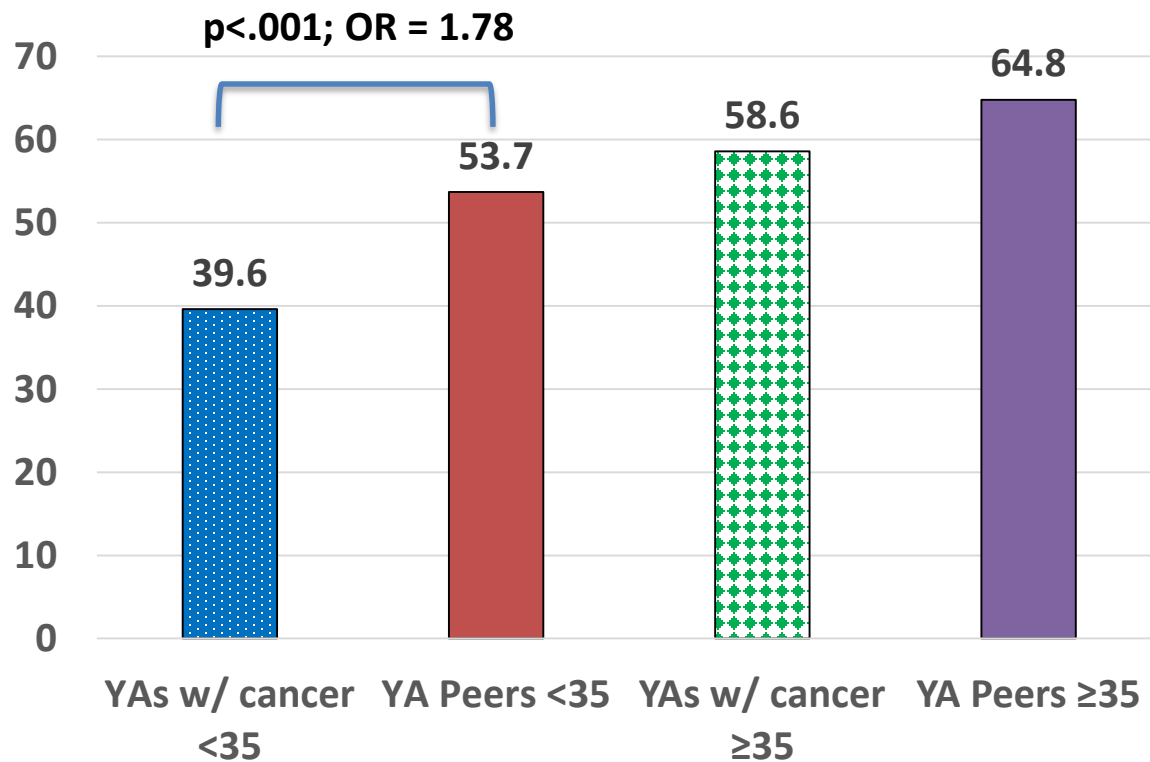
Assets by Current Age



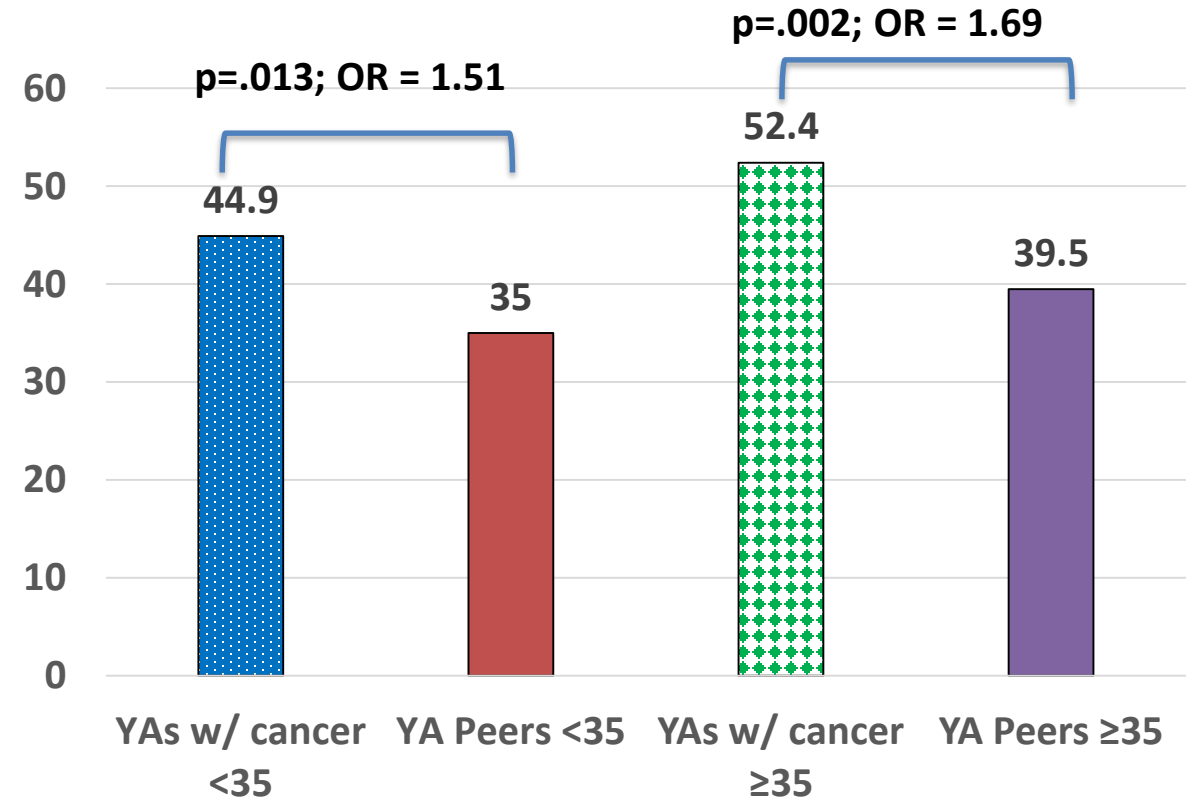
Debts and Liabilities by Current Age

Total value of debts and liabilities was $p < .001$ for YAs 34 and under and for YAs 35 and older

Percentage of YAs with a Mortgage

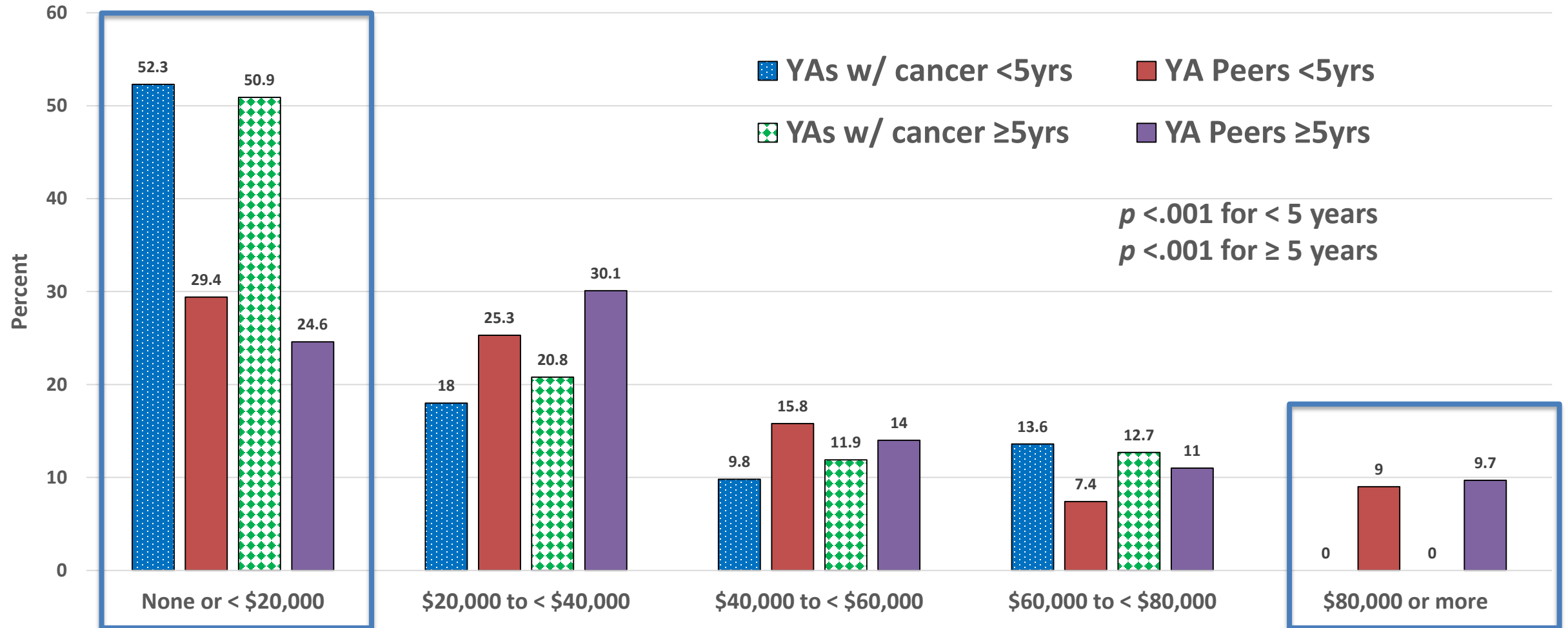


Percentage of YAs with an Outstanding Credit Card Balance

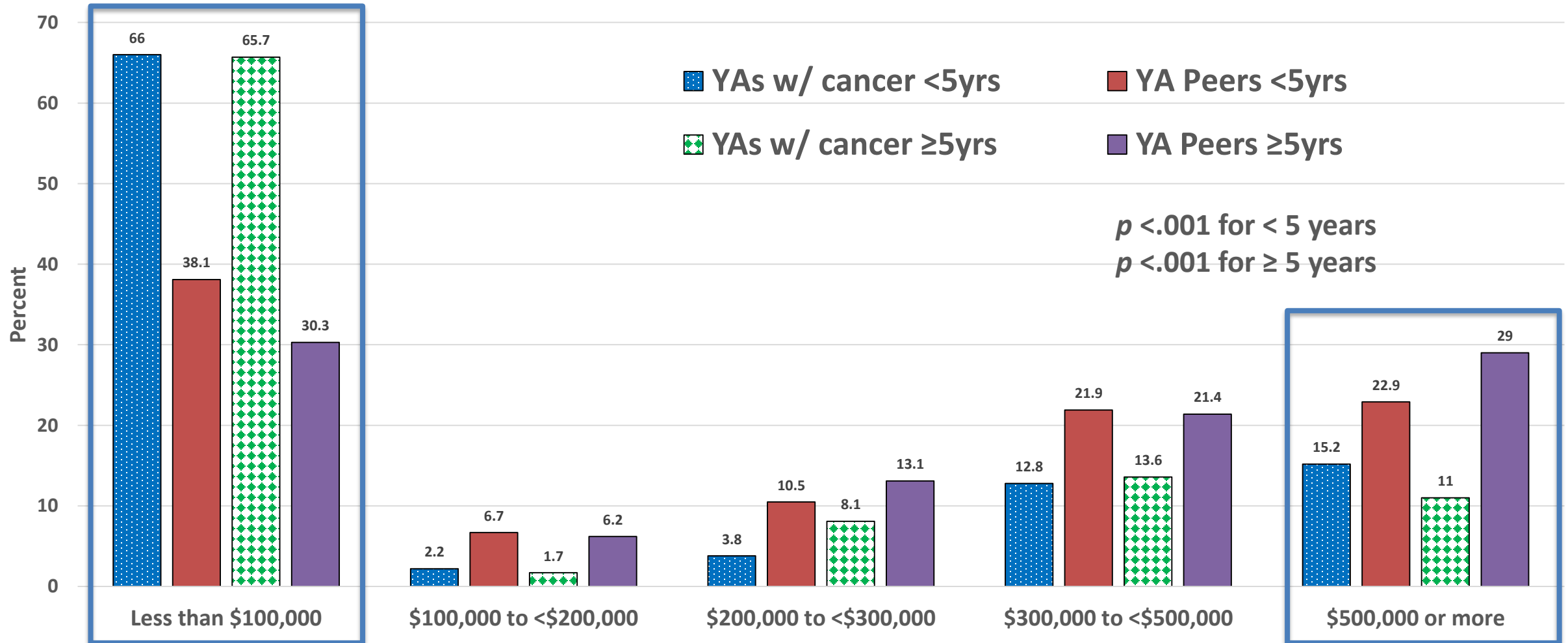


Do YAs With Cancer Recover Financially The Further They Are From Diagnosis?

Personal Income by Time Since Diagnosis

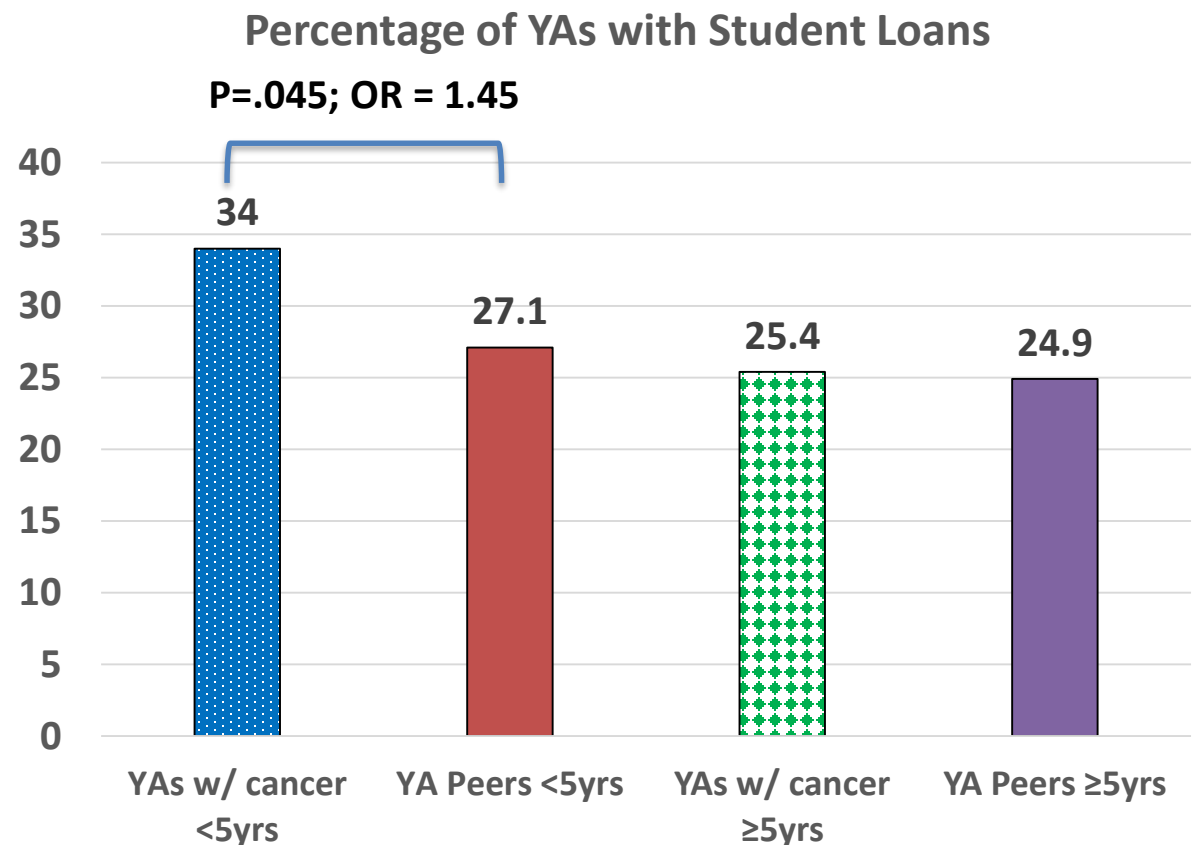
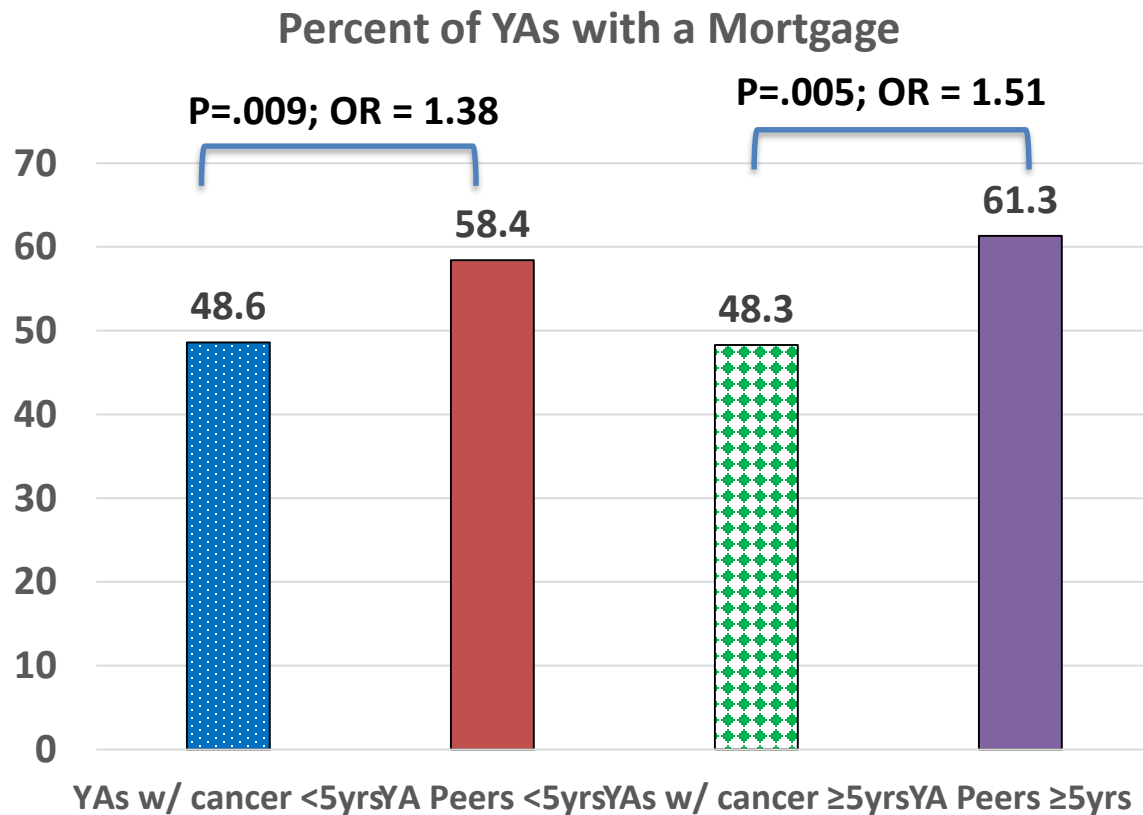


Assets by Time Since Diagnosis



Debts and Liabilities by Time Since Diagnosis

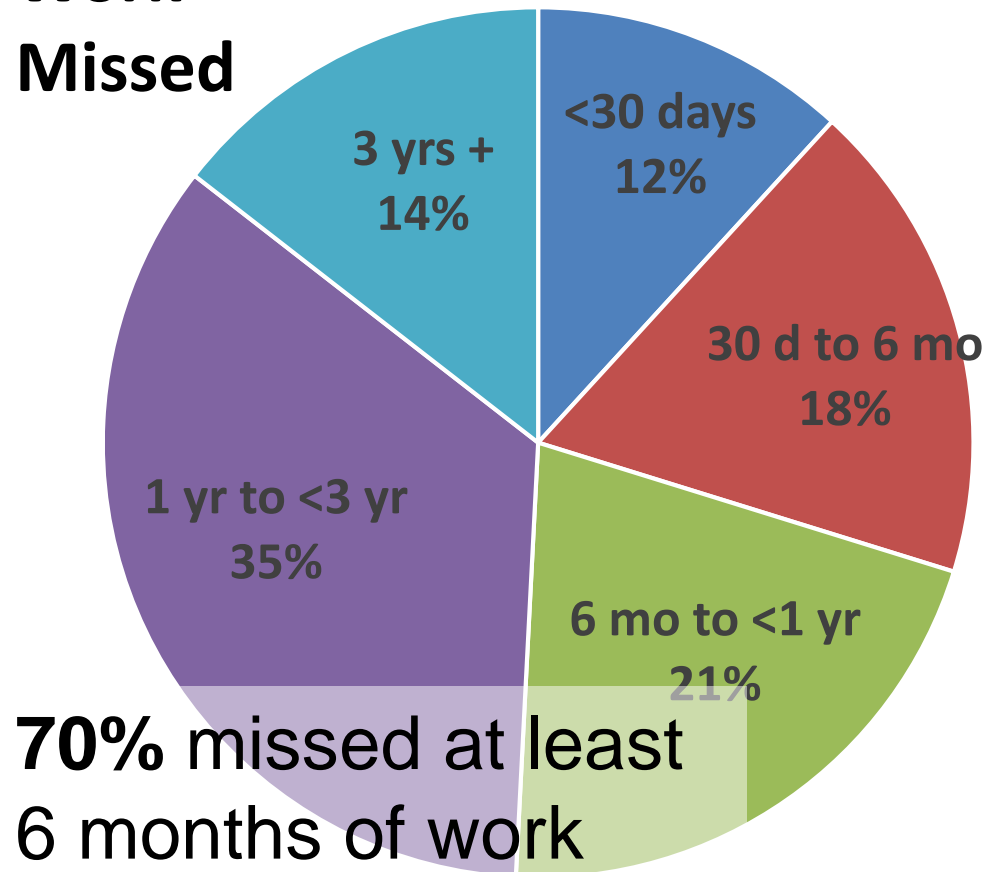
Total value of debts and liabilities was $p < .001$ for YAs < 5 years and for YAs ≥ 5 years since diagnosis



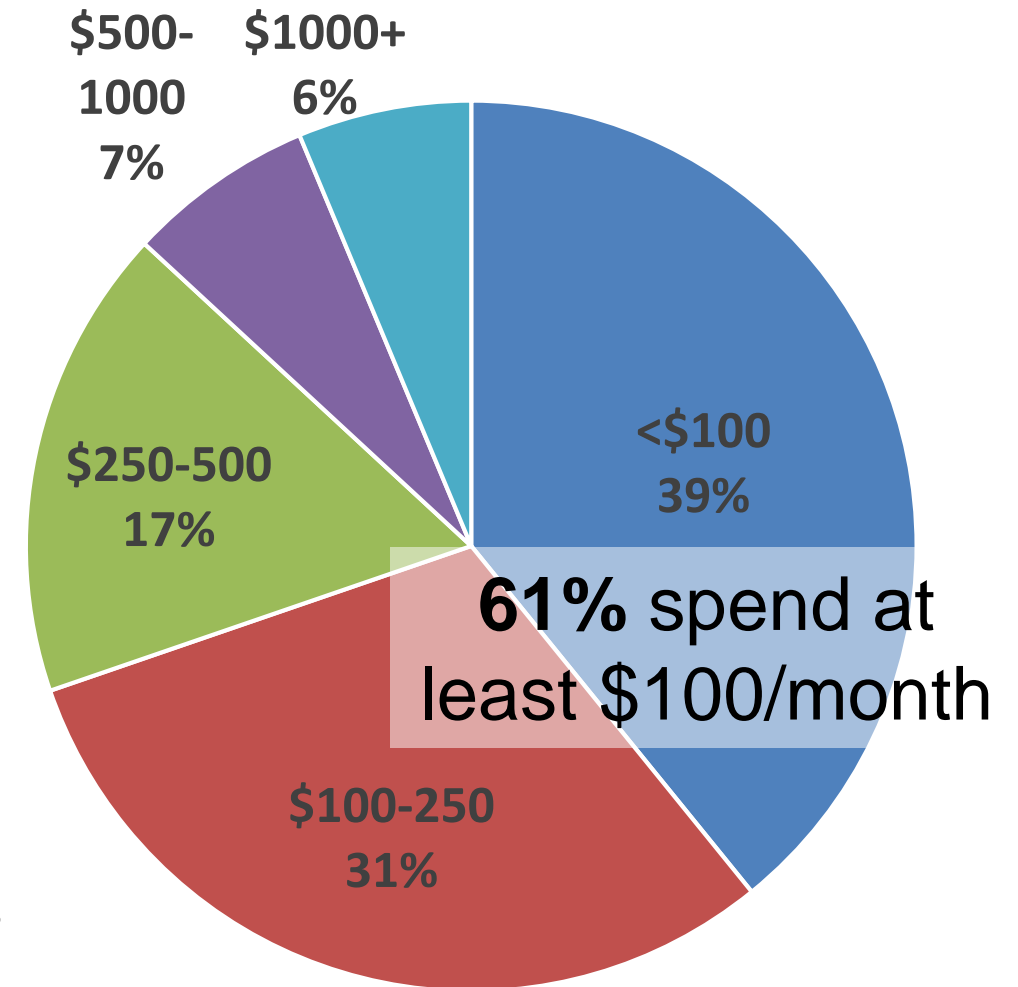
How Do Out Of Pocket Expenses And Time Off Work Contribute To This Financial Impact?

Work Missed and Monthly Cancer Expenses

Work Missed



Monthly Cancer Expenses



Implications

- This is the first and largest study to examine the specific financial impact of cancer in young adults in Canada
- We demonstrate a pervasive and persistent economic impact of cancer on YAs compared to non-cancer peers.
- It is vital that the government, cancer care institutions, labor force organizations, disability programs, and industry develop policies to address the economic status of YA cancer survivors.
- The development of programs that provide life-long support and rehabilitation is critical.

Thank You!



YAC Prime Implications for YA's



YAC Prime will help...

1. Normalization
2. Make YACC better
3. Enhance YACC's capacity by supporting fund-raising initiatives
4. Support increased advocacy to help more young adults living with, through and beyond cancer

Thank you!



**We've got their backs only because
you have ours.**

Liz Entrop, YACC Alumni & Stage 4 Uterine
Cancer Survivor

