



Réseau de
cancérologie
Rossy

Rossy
Cancer
Network

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How can we best meet the unique needs of Adolescent and Young Adults (AYAs) with cancer?

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Agenda

- Canadian statistics
- RCN statistics
- AYA's perception of care
- Findings from the AYA Delphi study
- Moving forward

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Who are Adolescent & Young Adults with cancer?

AYAs are a unique group of patients in terms of the **biology** their cancers, their **psychosocial needs** and the way they **experience cancer journey**



Definition - Age Brackets

Lower age limit: 18 years
Upper age limit: 39 years

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Challenges in defining the age AYA brackets...

- **U.S:**

- *The 2006 Surveillance Epidemiology and End Results (SEER):* 15–29 age
- *The 2006 Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG) :* age 15–39
- NCI: age 15-39
- JAYAO: age 15-39

- **Australia: CanTeen:** age 12–24.

- **U.K:**

- *The Teenage Cancer Trust:* age 13–24.
- *EUROCARE:* age 15-24.

- **Canada:**

- Cancer Care Ontario: age 15-29
- Canadian Task Force: Canadian Cancer Statistics (2009); age 15-29
- McGill AYA Oncology Program: 18-39



Most common cancers by age

FIGURE 1
Most common cancers by age



Figure 1
Based on rates age-standardized to the 2011 Canadian population. Data exclude the territories.
QC: Data were not available for 2011, 2012 and 2013. The 2010 data were therefore used for 2011, 2012 and 2013.
Data Source: Statistics Canada, Canadian Cancer Registry; *Canadian Cancer Society, Canadian Cancer Statistics.



Trends in incidence

Between 1992 and 2013, there was an increase in the age-standardized incidence rate of cancer for the AYA population.



□ Highest increase in age – standardized incidence

- Colorectal
- Thyroid

□ Decrease in incidence

- Soft-tissue sarcomas (likely due to the decline
- of Kaposi sarcoma related to HIV/AIDS.
- Non-Hodgkin lymphoma

FIGURE 2
Percent change between 1992-96 and 2009-13 in age-standardized incidence rates for different cancers

- 15-29 years
- 30-39 years

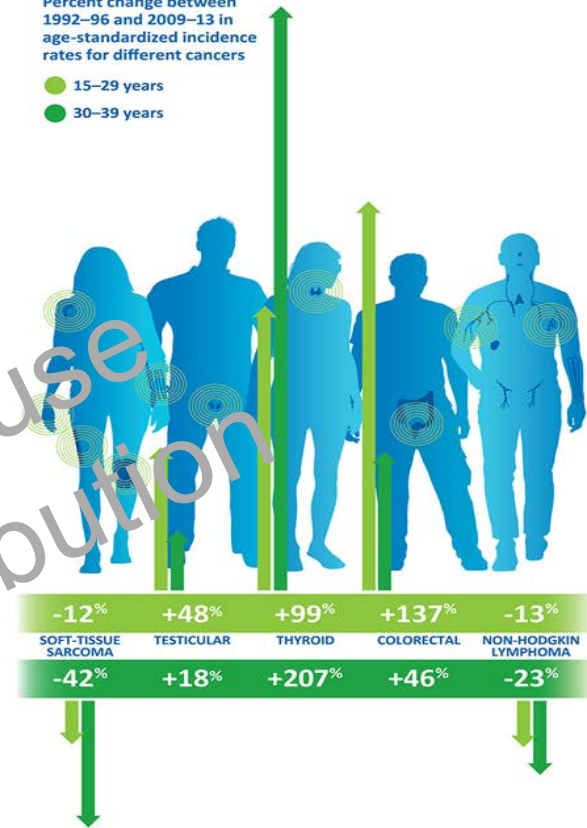


Figure 2
Data exclude the territories.
QC: Data were not available for 2011, 2012 and 2013. The 2010 data were therefore used for 2011, 2012 and 2013.
Data source: Statistics Canada, Canadian Cancer Registry.



Five –Year Relative Survival by Cancer Type and Age Group

TABLE 1

FIVE-YEAR RELATIVE SURVIVAL RATIO BY CANCER TYPE AND AGE GROUP, CANADA — 2004–08		
	15–29 Years	30–39 Years
CANCER TYPE	RATIO	RATIO
Thyroid	99.6	99.8
Hodgkin lymphoma	96.4	93.5
Testis	95.8	97.2
Melanoma	94.2	92.7
Uterus	92.2	90.5
Cervix	87.9	87.3
Ovary	87.1	77.8
Ependyoma	85.5	93.9
Low-grade astrocytoma	85.1	73.8
Non-Hodgkin lymphoma	83.4	81.1
Breast	83.1	84.1
Soft-tissue sarcoma	69.9	73.2
Colorectal	66.2	68.3
Acute lymphoid leukemia	66.0	61.2
Acute myeloid leukemia	66.0	55.3
Bone	62.4	71.6
Medulloblastoma	50.7	63.1
Glioblastoma	26.5	25.8
All Cancers	86.3	83.4

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Table 1
Data exclude QC and the territories.
Data source: Statistics Canada, Canadian Cancer Registry.



Five year relative survival ratios

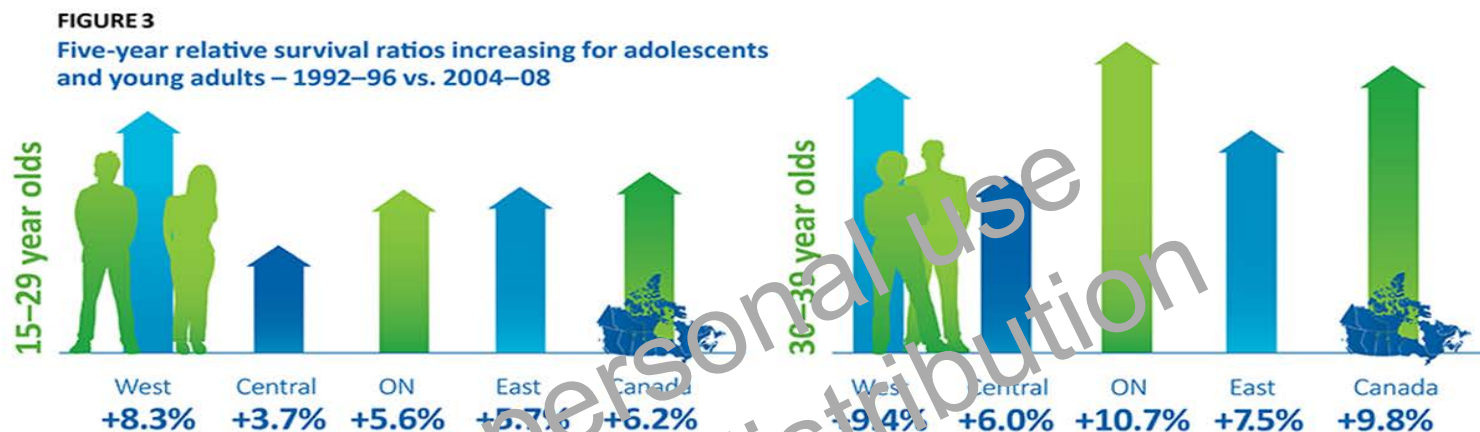


Figure 3
West includes AB and BC; Central includes MB and SK; East includes NB, NS, NL and P.E.I. Data exclude QC and the territories.
Data source: Statistics Canada, Canadian Cancer Registry.



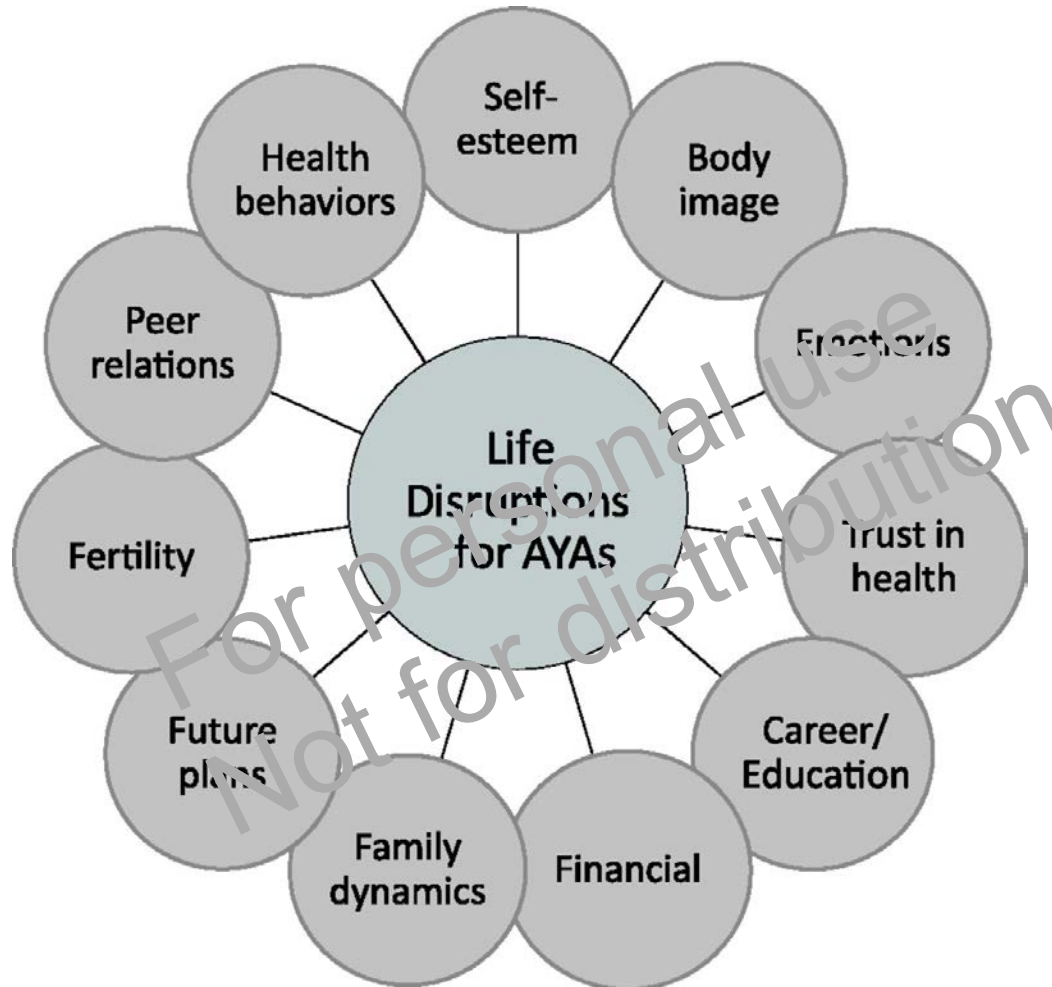
Characteristics of the late adolescence and early adulthood life stage:

- Development of identity
- Pursuit of
 - higher education
 - career development
- Achievement of financial independence
- Forming of romantic/intimate relationships
- Family planning
- Providing for young children

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Possible life disruptions for AYAs



Sharyl J. Nass et al. The Oncologist 2015;20:186-195



Psychosocial aspects of cancer diagnosis and treatment

- Data suggests that AYA's psychological **distress exceeds population norms** at the *time of diagnosis* and *at the time of the transition to survivorship*¹
- A large proportion of AYAs report unmet needs for counseling and other forms of psychosocial support²
- A prevalence of psychological distress *does not vary by the type of cancer or the prognosis* (a trend that is observed in adult cancer population)³
- Research suggests that **interventions with the aim of managing cancer -and treatment -related symptoms and facilitating involvement in work or school may have the greatest effect in terms of reducing distress**⁴

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1. Kwak M, Zebrack BJ, Meeske KA, et al. Trajectories of psychological distress in adolescent and young adult patients with cancer: A 1-year longitudinal study. J Clin Oncol 2013;31:2160-2166.
2. Keegan THM, Lichtensztajn DY, Kato I, et al. Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study. J Cancer Surviv 2012;6:239-250
3. Zabora J, BrintzenhofeSzoc K, Curbow B, et al: The prevalence of psychological distress by cancer site. Psychooncology 10:19-28, 2001
4. 1. Kwak M, Zebrack BJ, Meeske KA, et al. Trajectories of psychological distress in adolescent and young adult patients with cancer: A 1-year longitudinal study. J Clin Oncol 2013;31:2160-2166



Late and long-term effects

System	Exposures	Potential Late Effects
Cardiovascular	Radiation therapy Anthracyclines Platinums	Myocardial infarction or stroke Congestive heart failure Valvular disease Hypertension
Pulmonary	Radiation therapy Bleomycin Carmustine/lomustine	Restrictive lung disease Pulmonary fibrosis Exercise intolerance
Renal/urological	Radiation therapy Platinums Ifosfamide/cyclophosphamide	Renal insufficiency, failure Hemorrhagic cystitis
Endocrine	Radiation therapy Alkylating agents	Obesity Infertility and gonadal dysfunction Dyslipidemia Insulin resistance and diabetes
Central nervous system	Radiation therapy High dose/intensified antineoplastic chemotherapy	Learning disabilities Cognitive dysfunction
Psychosocial	Cancer	Affective disorders (anxiety, depression) Post-traumatic stress Sexual dysfunction, relationship problems Employment and educational problems Insurance discrimination Adaptation and problem solving
Second malignancies	Radiation therapy Alkylating agents Epidodophyllotoxins	Solid tumors Leukemia Lymphoma

Sources: [5, 52].

Sharyl J. Nass et al. The Oncologist 2015;20:186-195

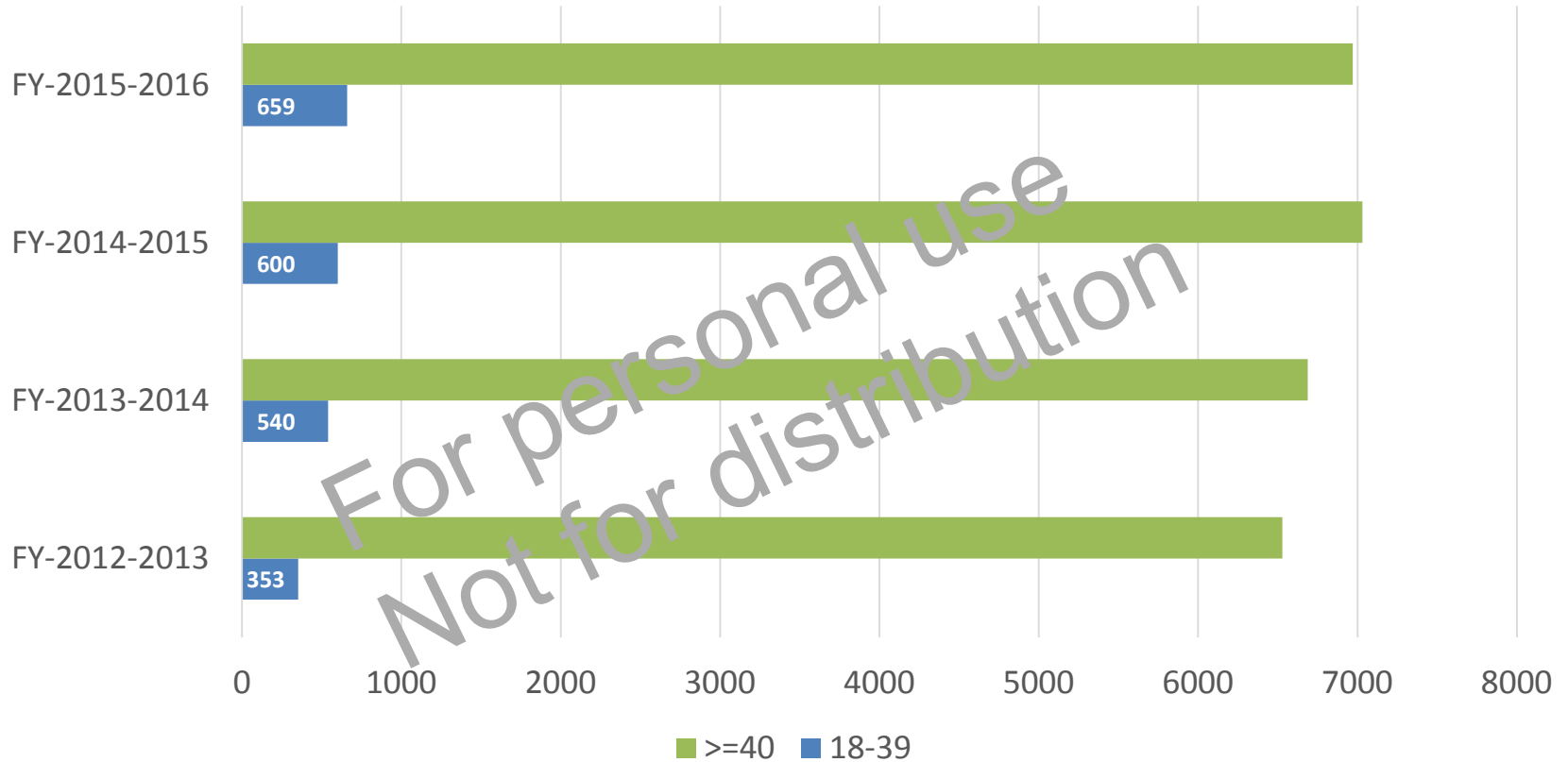


AYA RCN Statistics at Glance

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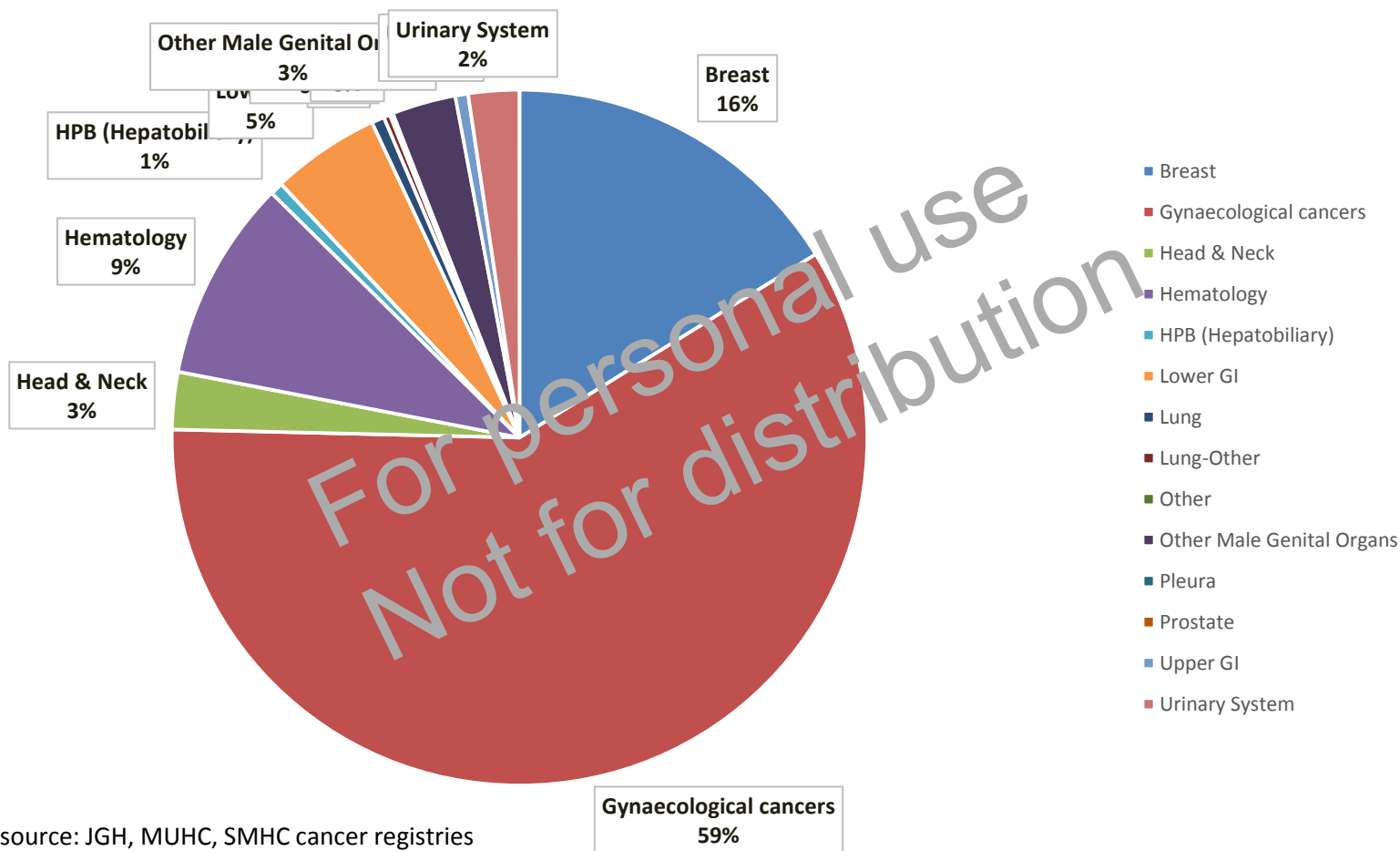
Number of patients with cancer by age groups RCN (FYs 2012 to 2016)



Data source: JGH, MUHC, SMHC cancer registries



Adolescent and young adult cancers (age 18-39) RCN (FY 2015-2016) N= 674



Where are AYAs currently treated in RCN?

- JGH (Adult Oncology Unit)
- SMHC (Adult Oncology Unit)
- MUHC (Adult Oncology Unit)
 - MNI
- Montreal Children's Hospital
- McGill AYA Oncology Program
 - Multidisciplinary team: hematologist/oncologists, radiation oncologists, GPs, psychiatrist, surgeons, pathologist, pharmacist, IPO + supportive care professionals (psychologist, social worker, occupational therapist, physiotherapist, a dietitian)
 - Open to patients diagnosed with cancer \geq 39 yrs. of age (and older adults suffering from pediatric type malignancies)



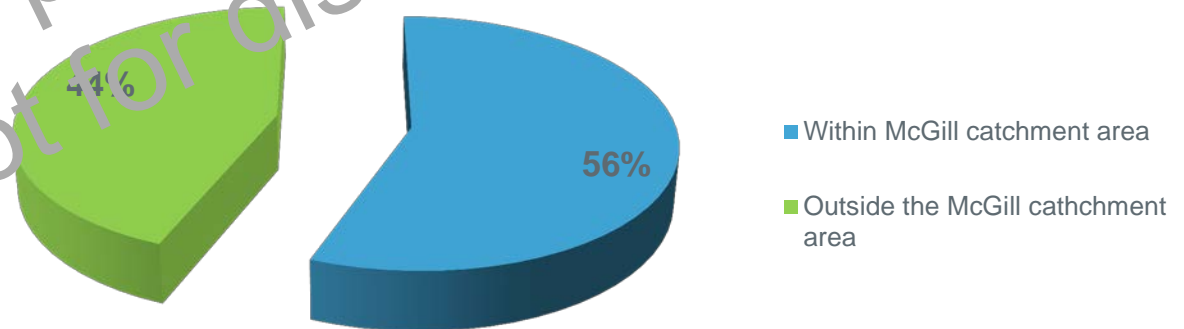
What are the reasons for referral to the McGill AYA Oncology Program ?

□ Reasons for referral:

- primary treatment (71%),
- second or third line treatment (19%),
- follow-up (7%),
- second opinion (3%)

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McGill AYA Oncology Program (referral source)



AYA's Perception of Care in RCN

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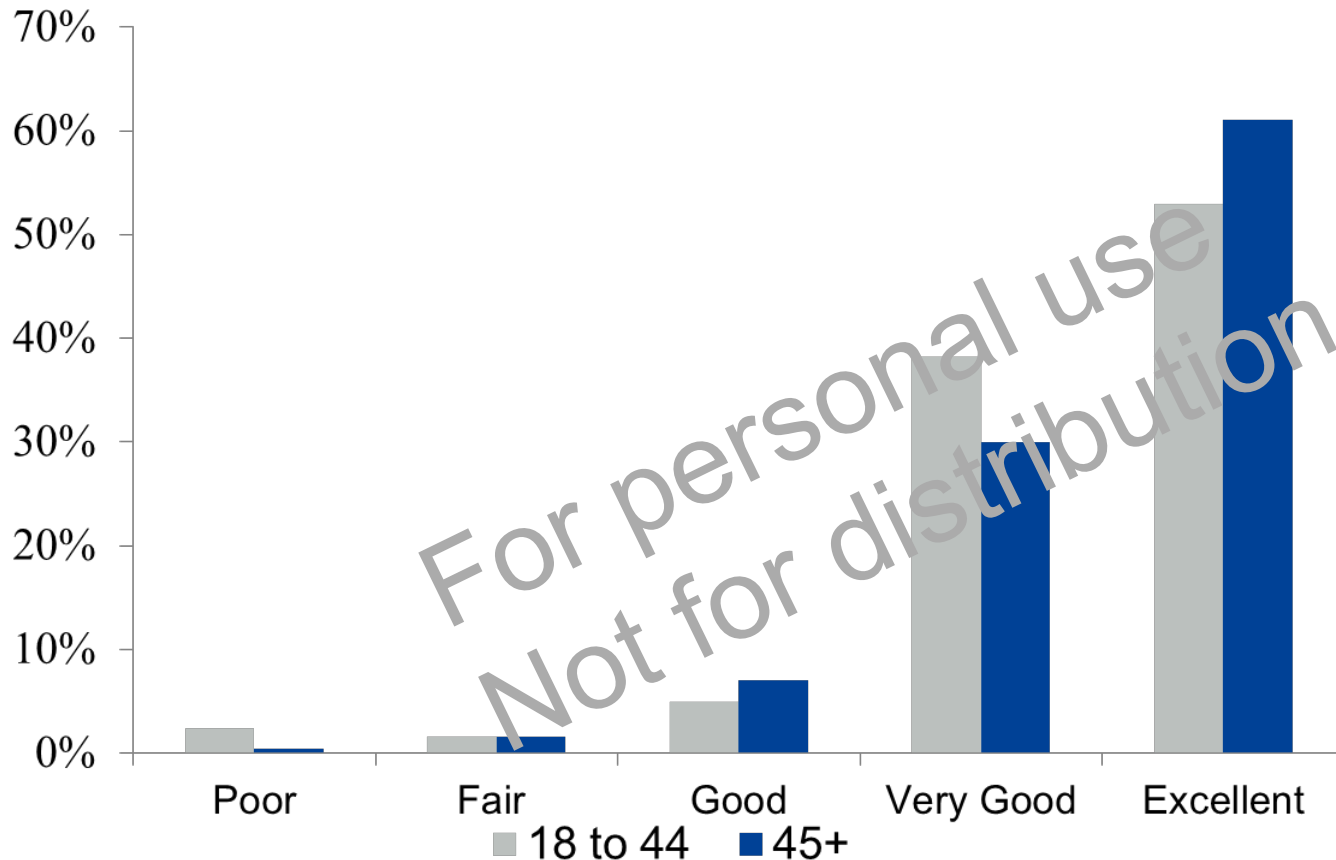


Results of the Ambulatory Oncology Patient Satisfaction Survey (AOPSS)

- Ambulatory Oncology Patient Satisfaction Survey is a standardized measurement tool used to assess the overall cancer experience
- The survey measures multiple domains of care (e.g. access to care, emotional support, coordination and continuity etc...)
- It is used in 7 Canadian provinces and internationally (US, UK)
- RCN has implemented the AOPSS in 2012
- To date, more than 2,500 patients in RCN completed the survey
- As part of our project, we compared AOPSS scores of patients age 18-44 (n=127) to AOPSS scores of patients age 45+ (n=2,163). The **Pearson Chi-Square test** was used to examine differences between the two data sets.



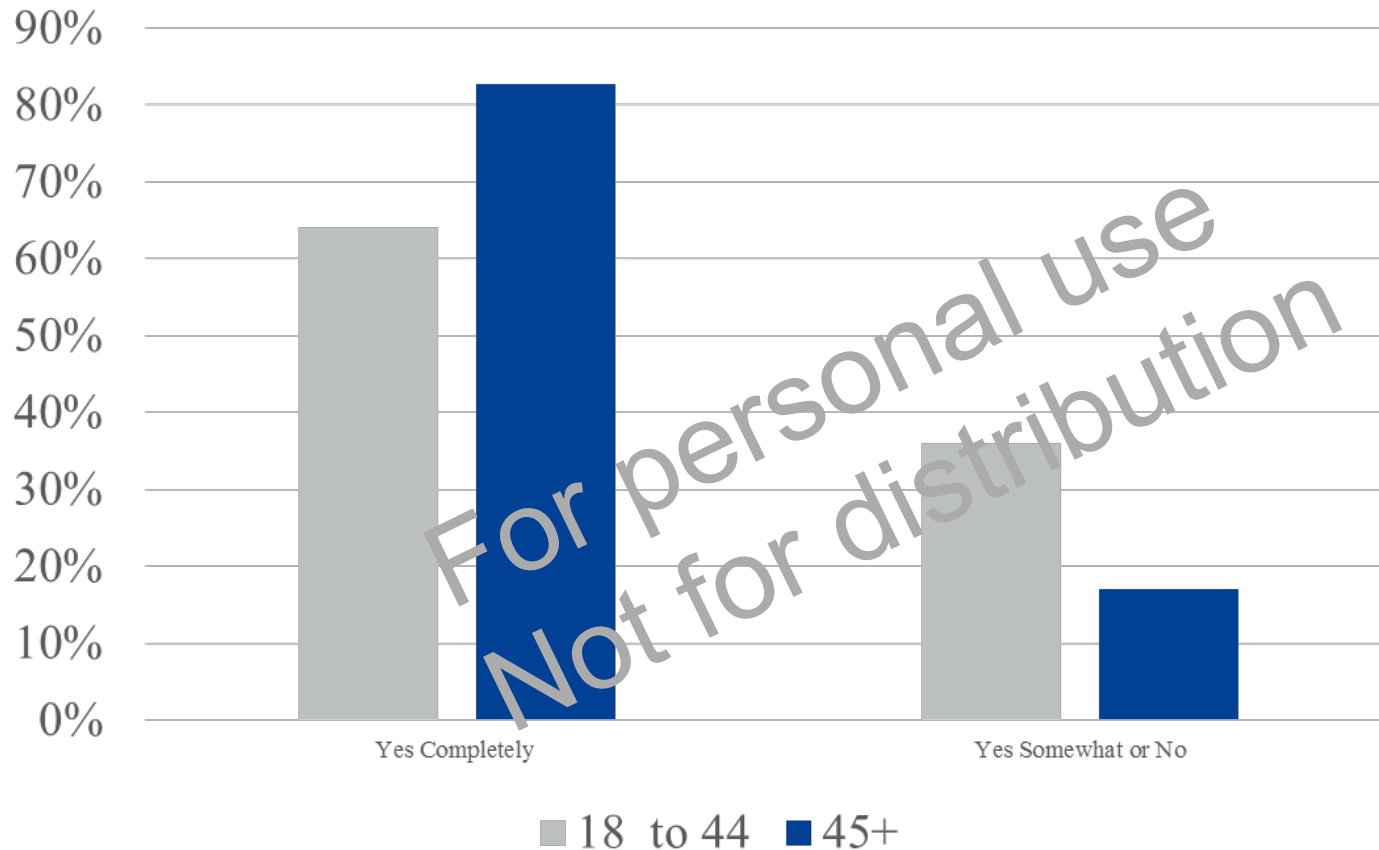
Q79: “Overall, how would you rate the quality of your care in the RCN hospitals in the past 6 months?”



Test	ChiSquare	p-value
Pearson	14.586	0.0056



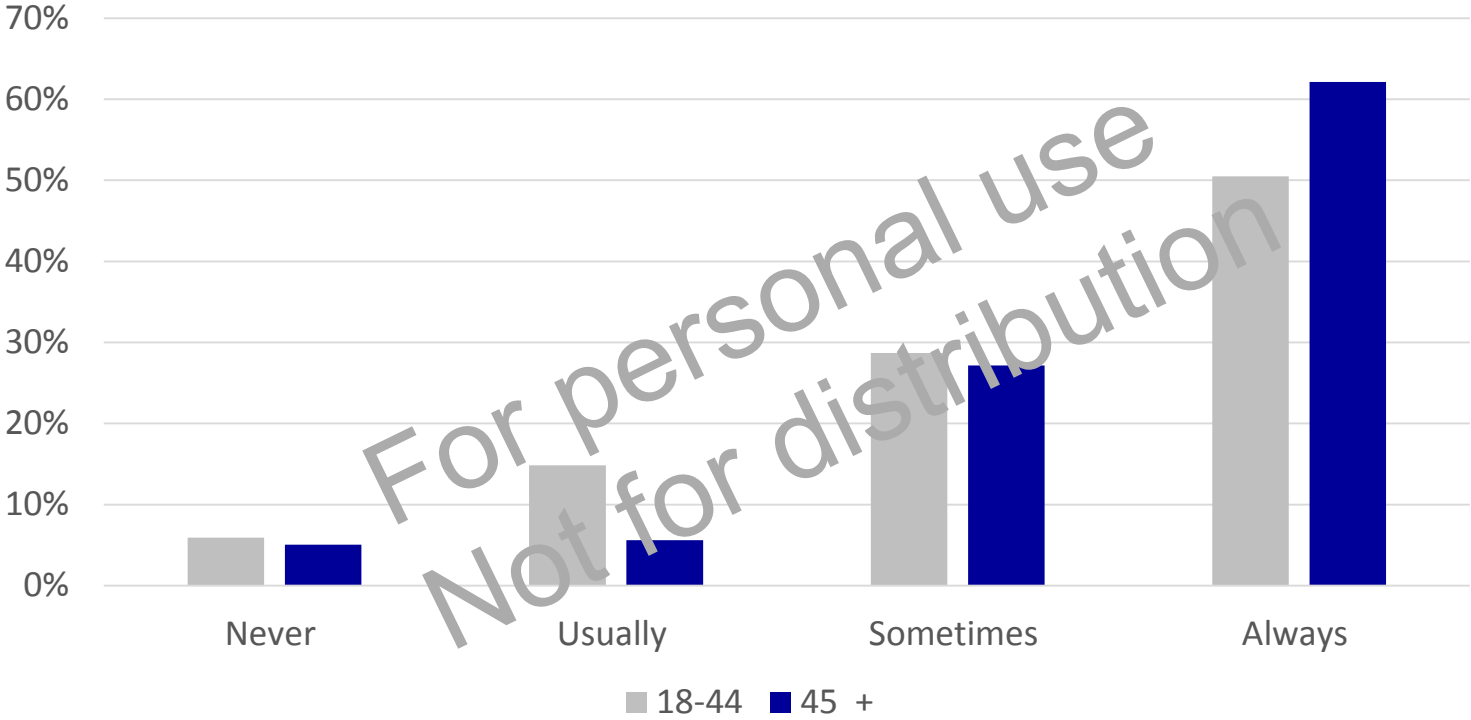
Q88: “In the past 6 months, did you receive all of the services you thought you needed for your cancer treatment?”



Test	ChiSquare	p-value
Pearson	5.537	0.0186

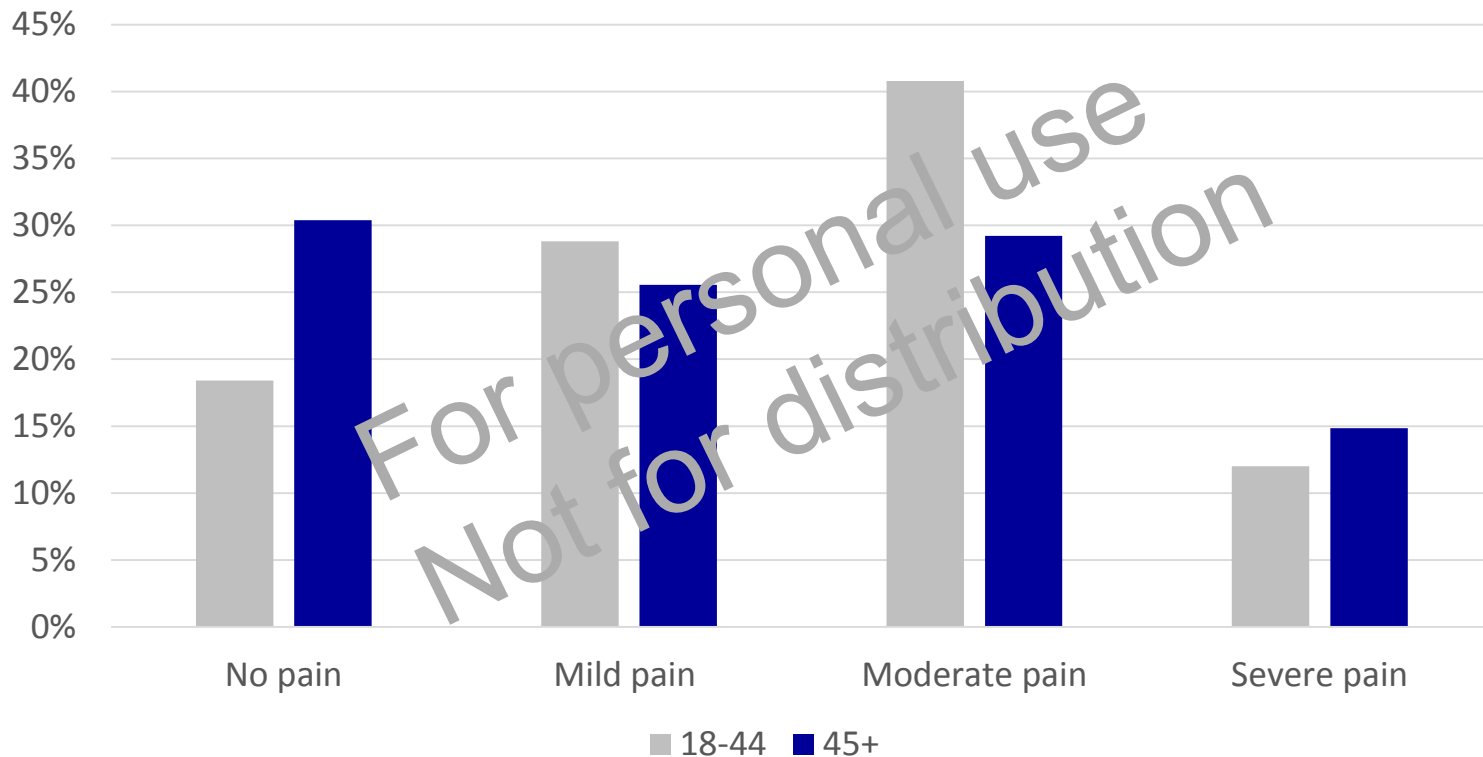


Q85: If you received cancer treatment at this hospital and somewhere else (at another hospital or clinic) do you feel that your overall care was well coordinated?



Test	ChiSquare	p-value
Pearson	15.57	0.0014

Q47: “ In the past 6 months, if you had pain on a scale 1-10, was it usually severe (7-10), moderate (4-6) or mild (1-3)?



Test	ChiSquare	p-value
Pearson	12.086	0.0071



AOPSS results- cont'd

- ❑ Compared to the patient population of age 45+, cancer patients age 18-44:
 - Have **higher need for emotional support** (how they rate the level of their emotional health, and how frequently they were referred for counselling re: anxieties)
 - Feel that they were **not involved** in decisions about their care as much as they wanted (e.g. listened to by CP, CP discussed patient worries, fears etc.)
 - Feel that they **did not get as much info** as they needed (nutrition, work, emotional/relationship changes)
 - Feel that often information was **not communicated** in a way they could understand (e.g. oral chemo instructions, test results etc, side effects, results of the surgery etc..)



Results of the RCN Delphi Study

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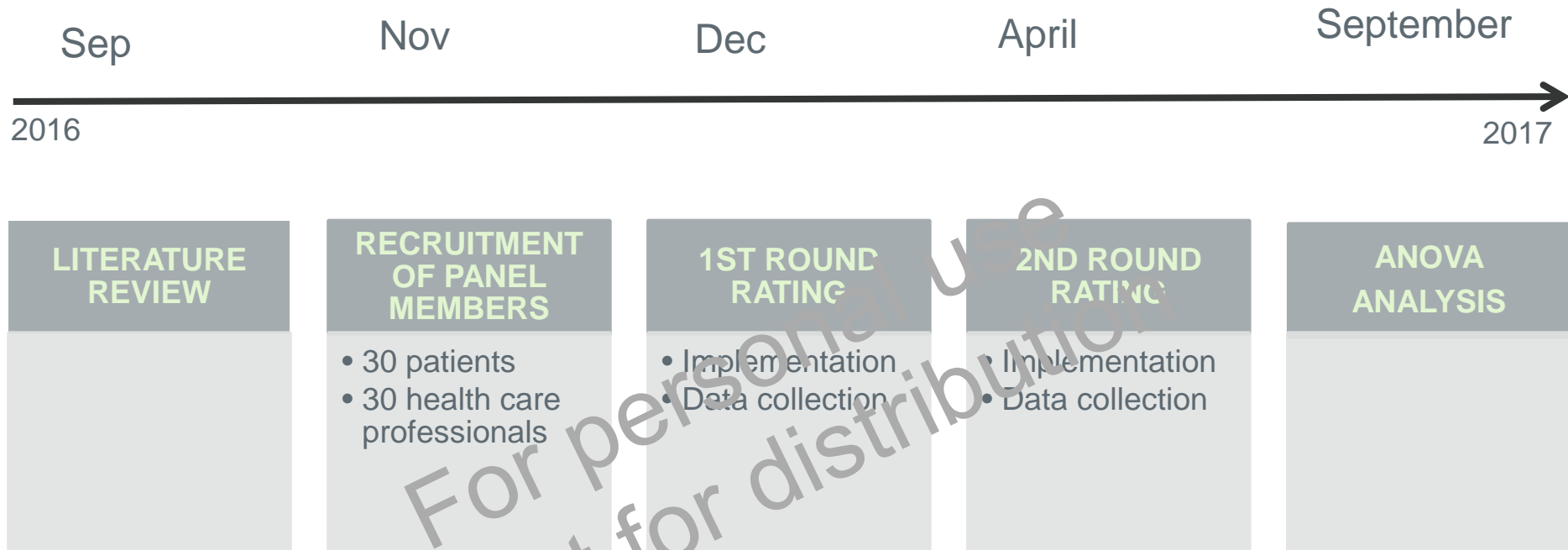
The Delphi technique

The Delphi technique is decision-making method used to obtain agreement or **consensus** among a group of **experts** on a particular issue through **systematic sequential rounds of survey administration.**

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The Delphi Timeline



A literature review identified **twenty - four sample strategies** (Zebrack et al, 2010) that could be incorporated in the current model of care to address AYA supportive care needs. **A Delphi panel** consisting of oncology health care professionals (HCPs) and AYA cancer patients rated the importance of each sample strategy on a 7-point Likert scale. **ANOVA** was performed to examine the differences between the two data sets. P- value ≥ 0.05 was used as a cut-off for significance.

Participant demographics of the Delphi Panels

TABLE 1

Participant Demographics: Healthcare Professionals Panel

Number of participants

Profession	Round 1 (n=31)	Round 2 (n=27)
Oncologist	6	6
Surgeon	5	3
Radiation Oncologist	2	1
General Practitioner	1	1
Medical Resident	1	1
Psychiatrist	2	1
Psychologist	3	3
Physiotherapist	1	1
Occupational Therapist	1	1
Social Worker	1	2
IPO Nurse	5	4
Dietician	1	1
Oncology Pharmacist	1	1
Patient Educator	1	1

TABLE 2

Participant Demographics: Patient Panel

Number of participants

Cancer Diagnosis	Round 1 (n=31)	Round 2 (n=21)
Breast	17	12
Lymphoma	2	2
Gastro-intestinal	5	3
Testicular	3	1
Sarcoma	3	2
Brain	1	1

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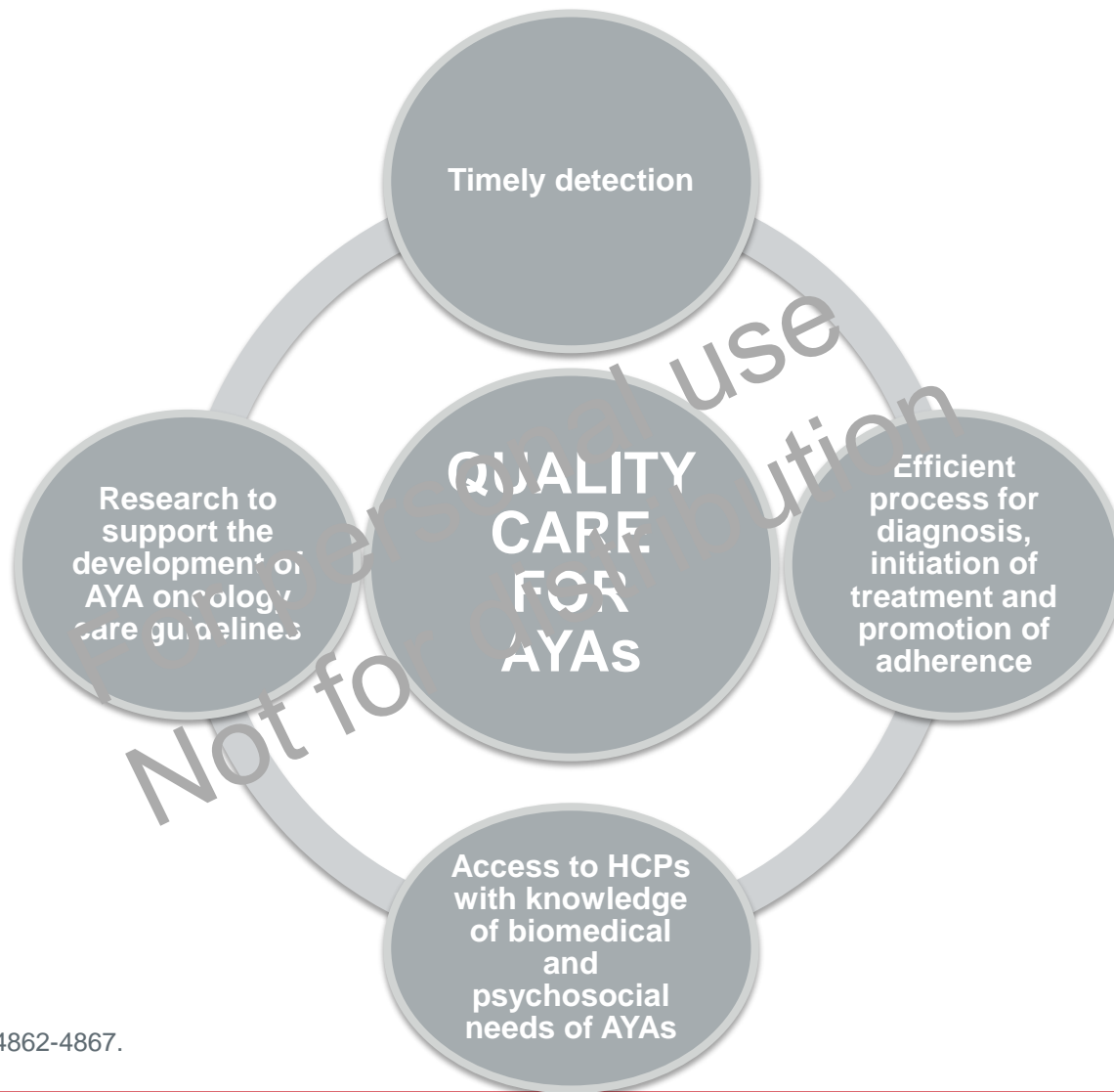


Top Three Ranking Sample Strategies to Improve QOL and Quality of Care Throughout the Cancer Care Continuum in the Rossy Cancer Network

	Combined Score (Patient Panel + HCP Panel)		HCP Panel (n=27)	Patient Panel (n=21)	ANOVA (p-value)
	Mean Importance Score	Rank	Mean Importance Score	Mean Importance Score	
Offer patient education programs that provide AYAs with knowledge regarding treatment options and the potential physical and QOL implications of cancer therapy	6.58	1 (tie)	6.59	6.57	0.91
Inform reproductive-age patients of cancer related fertility risks as early in treatment planning as possible (per the ASCO guideline 24) and refer as needed to an appropriate fertility preservation specialist	6.58	1 (tie)	6.63	6.52	0.58
Provide access to a systematic and standardized symptom management, pain control, and palliative care program	6.5	2	6.7	6.24	0.01
Make survivorship care plans available to patients and other appropriate health care providers	6.27	3	6.26	6.29	0.90



In conclusion



Zebrack et al. J Clin Oncol 28:4862-4867.



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Moving forward.....

- As a network, how do we best respond to unique care needs of AYAs with respect to:
 - Timely detection of patient needs
 - Patient education
 - Development of and access to AYA specific patients education programs
 - Development of AYA specific patient education material
 - Patient activation/ self-management behaviors
 - Triage and referral to the appropriate supportive care services
 - Improved coordination of care with family physicians
 - Improved adherence to treatment protocols
 - Participation in clinical trials



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