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Haematologist

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Saturday, August 13, 2016 (Room 5)

16:30 - 17:30 WS #131: Adolescent and Young Adult Cancer Service Provision - Can We Do It Better?

Standards of Care
for AYA cancer patients in NZ

Tristan Pettit August 2016

Talk outline

1. The AYA oncology survival disparity
   - International
   - New Zealand
2. Rationale behind the NZ AYA Standards of Care
3. Key Contributing Factors to AYA cancer care
4. Concept of Developmentally Appropriate Care
   - A youth health approach
5. Brief description of the NZ AYA Standards of Care.

AYA survival trends

- Albritton K, Bleyer W. Eur J Ca. 2003.
  - In 1975, a >10% survival advantage was noted in the 15-19 year age group when compared to the <15 year old age group, by 2000, this had flipped to a **7 % survival disadvantage**.
  - In US survival data, from 1975-1998, paediatric (0-15) and adult (>45) oncology experienced a survival improvement of 1.74% per year, whilst the 15-19 year group's rate of 0.9% **was almost 50% inferior**.
- Pichler et al. BJH. 2013
  - In a 25 year review of AYA vs Paediatric ALL outcome in European BFM based protocols, 5 year event-free survival (EFS) was 17% worse and 5 year overall survival 15% worse for AYA compared to paediatric groups.
  - Treatment related morbidity was main factor identified.

ELSEVIER

European Journal of Cancer 39 (2003) 2584–2599

European Journal of Cancer

www.ejconline.com

The management of cancer in the older adolescent

K. Albritton[a,1], W.A. Bleyer[b,*]

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Received 25 May 2003; received in revised form 5 September 2003; accepted 11 September 2003

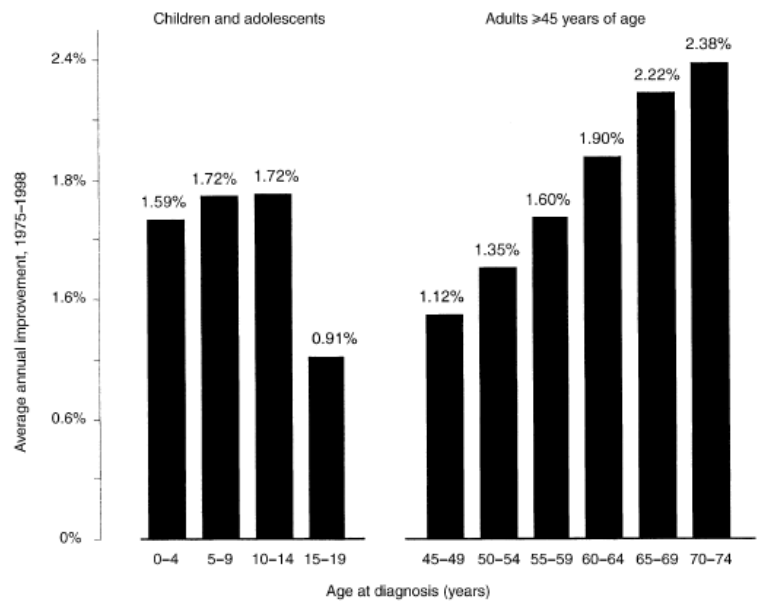


Fig. 1. Average annual percent improvement in the 5-year survival rate among United States (U.S.) cancer patients less than 20 years and 45 years and older at diagnosis. The average annual percent change was derived as a function of patient age from linear regressions of the rates during 1975–1980, 1981–1986, 1987–1992 and 1993–1988 [1]. Data from the U.S. Surveillance, Epidemiology and End Results (SEER) programme [3].

The distinctive biology of cancer in adolescents and young adults

Archie Bleyer‡, Ronald Barr§, Brandon Hayes-Lattin||, David Thomas¶, Chad Ellis# and Barry Anderson**, on behalf of the Biology and Clinical Trials Subgroups of the US National Cancer Institute Progress Review Group in Adolescent and Young Adult Oncology*

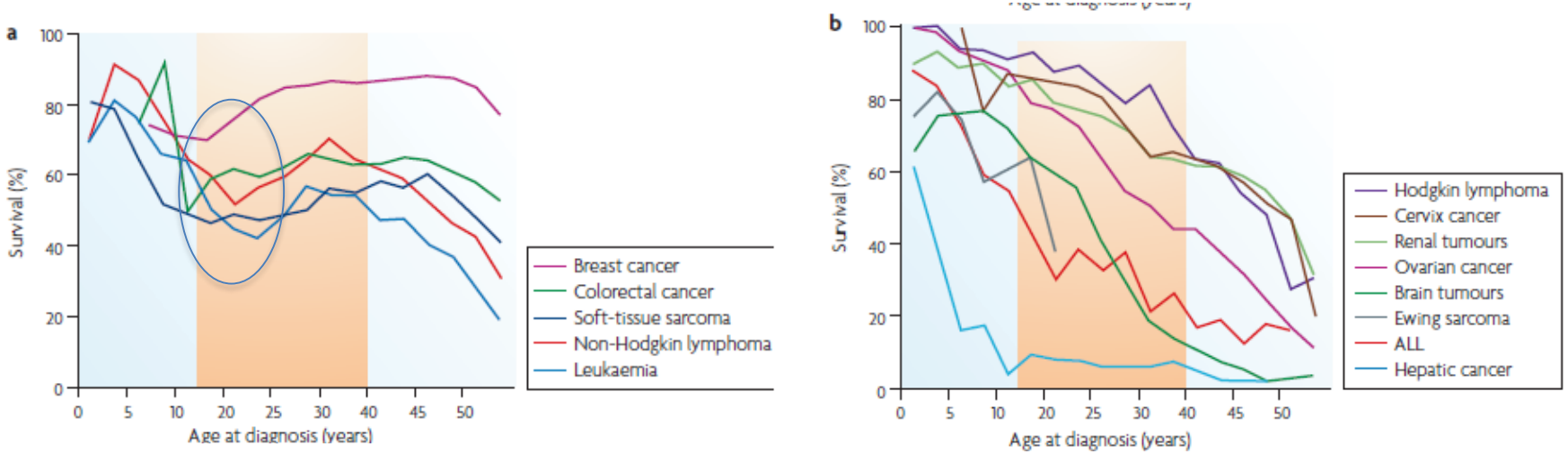


Figure 3 | **Cancers with 5-year relative survival rates that are lower in adolescents and young adults (AYAs) than in younger or older patients.** Data from US Surveillance Epidemiology and End Results (see URL in Further information) 1993–1997. The yellow background zone indicates the 15–39-year age range. **a** | Cancers that have a lower survival in AYAs than in both younger or older patients. **b** | Cancers that have a lower survival in AYAs than in younger patients. Adapted, with permission, from REF. 3 © American Cancer Society (2007).

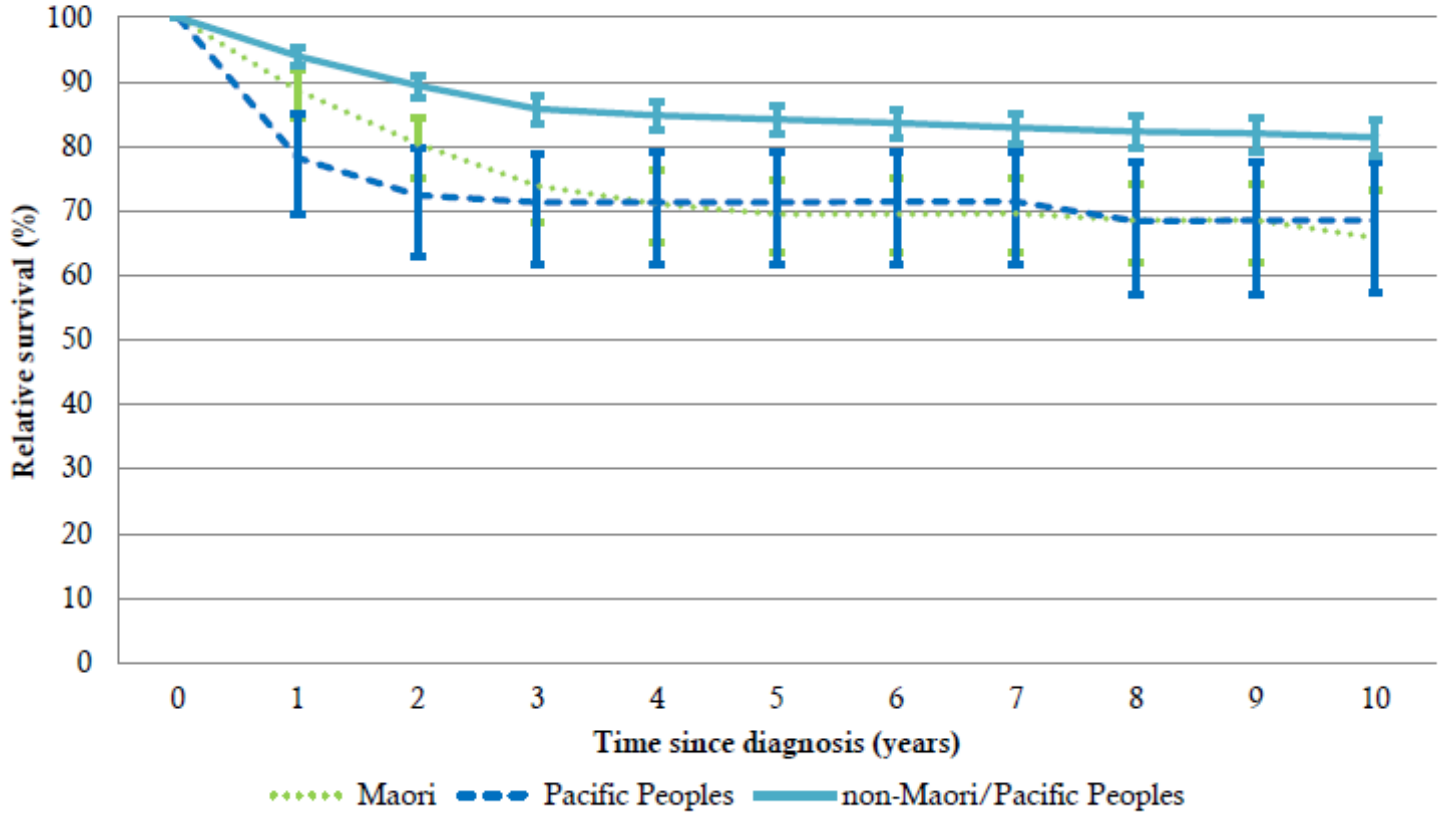
Nat Rev Cancer. 2008 Apr;8(4):288-98. doi: 10.1038/nrc2349.

NZ AYA survival

- A report of New Zealand adolescent and young adult cancer incidence and survival from 2000-2009 has shown that:
  - In comparison, New Zealand five-year relative survival (5YS) for the 15-24 year age group (80.6%) was significantly lower than reported by the European EUROCARE group (87.4%).
  - The New Zealand 5YS for adolescents 15-19 years (75.1%) was also significantly lower than the survival reported by the United States (81.8%) and Canada (81%) for comparable time periods

Ballantine, K., Sullivan, M. (2013). Adolescent and young adult cancer incidence and survival in New Zealand 2000-2009: Auckland: National Child Cancer Network.

Figure 4.5 Overall AYA cancer relative survival (including 95% CI), by ethnicity, New Zealand, 2000-2009



Ballantine, K., Sullivan, M. (2013). Adolescent and young adult cancer incidence and survival in New Zealand 2000-2009: Auckland: National Child Cancer Network.

AYA CANCER NETWORK AOTEAROA

ADVANCING CANCER CARE FOR 12-24 YEAR OLDS

- Formed in 2013
- As part of 5 year national strategy, proposal for a model of care
  - equitable access regardless of domicile.
  - high quality medical and psychosocial care
- ‘Service Provision for Adolescent and Young Adult Cancer Patients in New Zealand including Standards of Care’
  - Standards of Care for short!

Standards Of Care (SOC)

- Summarises the level of care that an AYA with cancer in NZ should receive.
  - Monitoring framework
    - benchmark delivery of care against best practice.
    - identify service areas of strength and need.
- The SOC will sit alongside the 11 Tumour Standards released by the Ministry of Health in 2012 and 2013.
- SOC developed by a working group representing the wider multidisciplinary/ multiagency AYA cancer care workforce.
  - 3 GP representatives on working group

Key Contributing Factors to AYA cancer care

1. Differences in range of tumours and biology
2. Low accrual on clinical trials and targeted AYA research
3. Optimal treatment site and differences in treatment strategies
4. Diagnostic Delay
5. Developmental Stage and Adherence
6. Psychosocial care

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Targetable Kinase-Activating Lesions in Ph-like Acute Lymphoblastic Leukemia

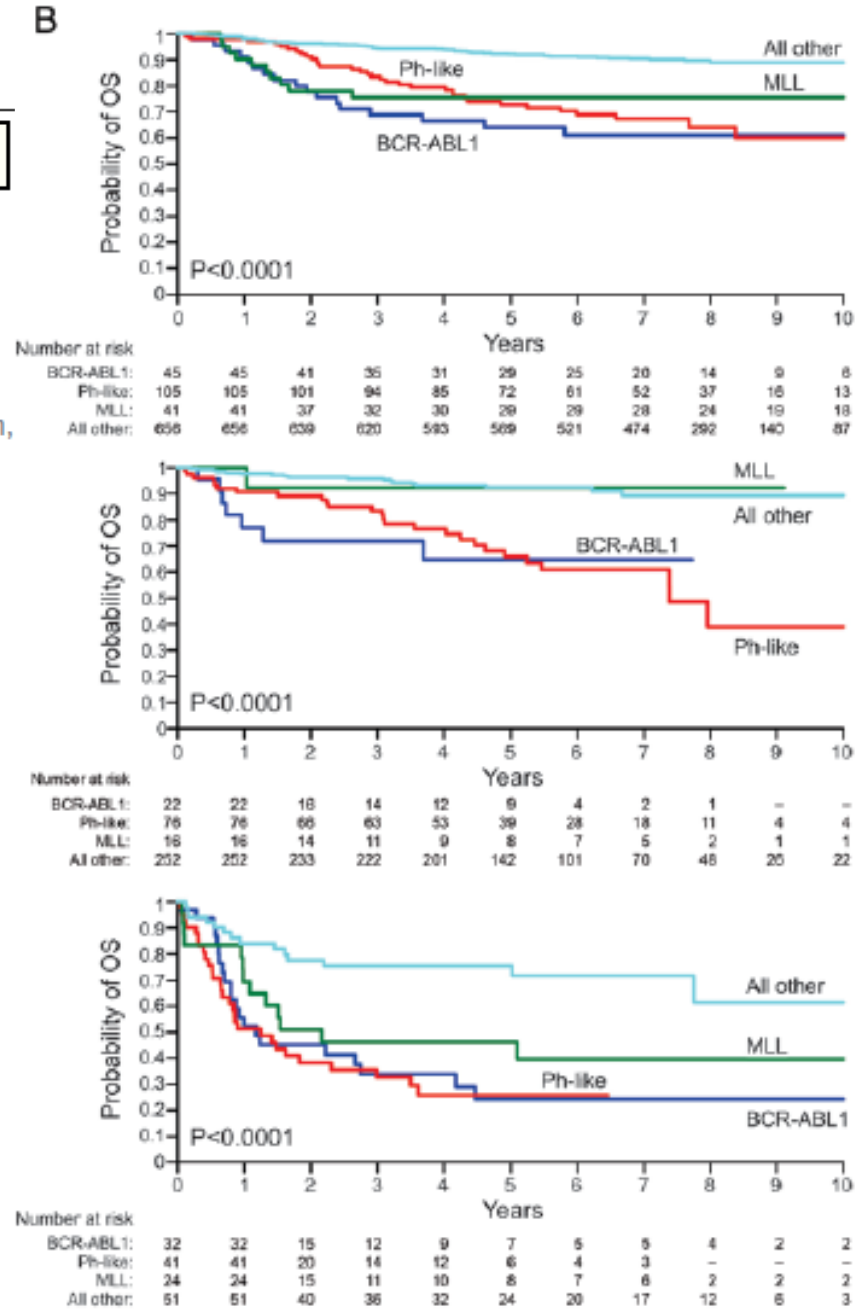
K.G. Roberts, Y. Li, D. Payne-Turner, R.C. Harvey, Y.-L. Yang, D. Pei, K. McCastlain,

RESULTS

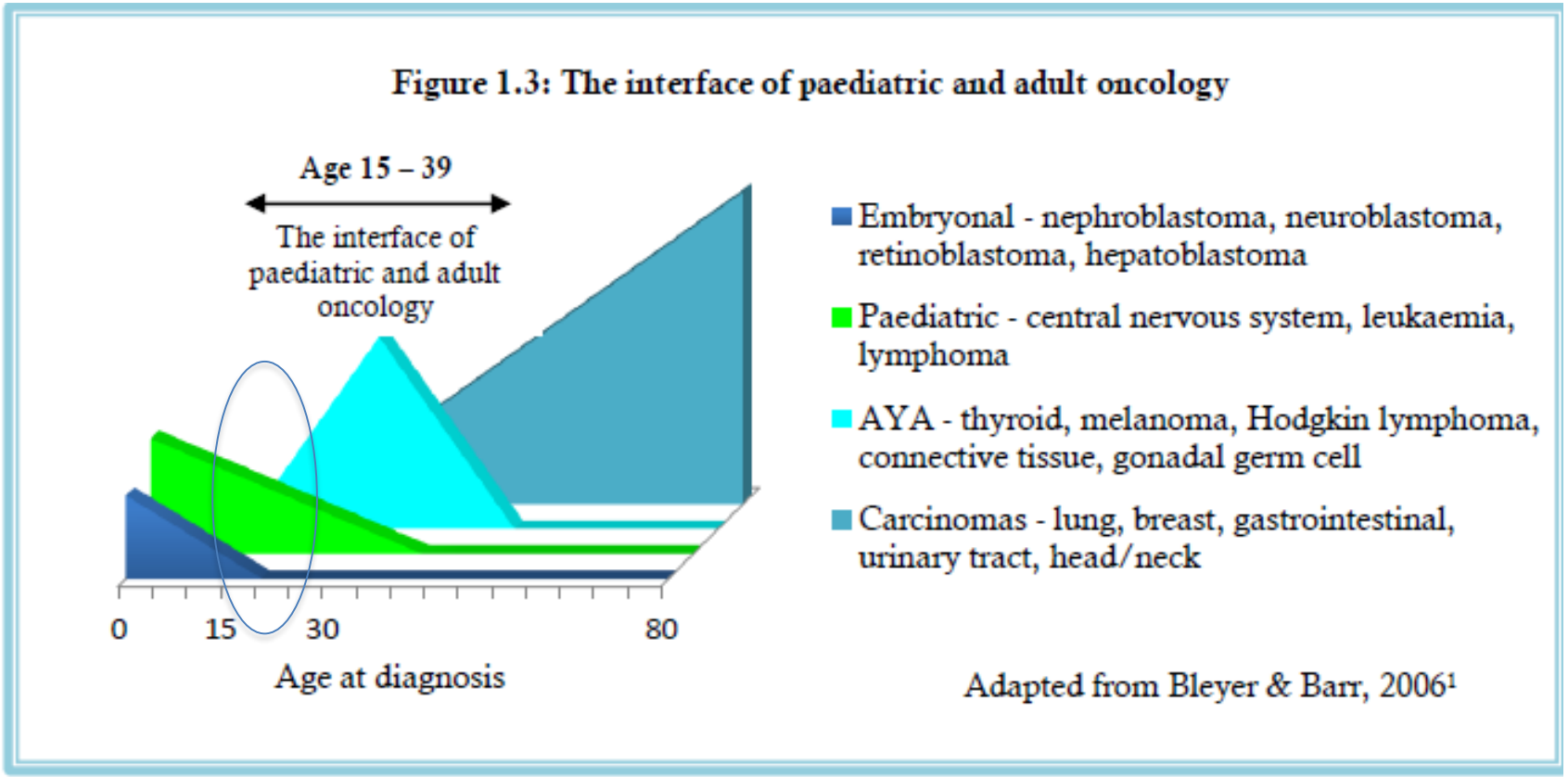
CLINICAL CHARACTERISTICS AND OUTCOMES

Overall, 264 of 1725 precursor B-cell ALL cases (15.3%) were identified as Ph-like ALL (Table S4 in Supplementary Appendix 2). The prevalence of Ph-like ALL significantly increased with age, from 10% among children with standard-risk ALL and 13% among those with high-risk ALL to 21% among adolescents with ALL and 27% among young adults with ALL (P<0.001 for the comparisons of children with adolescents and children

N Engl J Med 2014;371:1005-15.
DOI: 10.1056/NEJMoa1403088



AYA – unique tumour group



Ballantine, K., Sullivan, M. (2013). Adolescent and young adult cancer incidence and survival in New Zealand 2000-2009: Auckland: National Child Cancer Network.

Available, accessible, aware, appropriate, and acceptable: a strategy to improve participation of teenagers and young adults in cancer trials

Lorna A Fern, Jennifer A Lewandowski, Katy M Coxon, Jeremy Whelan, for the National Cancer Research Institute Teenage and Young Adult Clinical Studies Group, UK

Under-representation of teenagers and young adults in clinical trials for cancer is acknowledged internationally and might account for the lower survival gains noted for this group. Little research has focused on strategies to increase participation of teenagers and young adults in clinical trials. We applied a conceptual framework for barriers to recruitment of under-represented populations to data for cancer clinical trials in teenagers and young adults. We did a systematic analysis of data for clinical trial enrolment in Great Britain over 6 years (2005–10), and reviewed the published work for the origins and scientific rationale of age eligibility criteria in clinical trials for cancer. Our Review revealed little scientific evidence for use of age eligibility criteria in cancer clinical trials. Participation in cancer trials fell as age increased. Between 2005 and 2010, participation rates increased for children and young people aged 0–24 years. The highest increase in participation was for teenagers aged 15–19 years, with smaller improvements in rates for 20–24 year olds. Improvements were related to five key criteria, the five As: available, accessible, aware, appropriate, and acceptable. In studies for which age eligibility criteria were appropriate for inclusion of teenagers or young adults or amended during the study period, participation rates for 15–19 year olds were similar to those for 10–14 year olds. We propose a conceptual model for a strategic approach to improve recruitment of teenagers and younger adults to clinical trials for cancer, with use of the five As, which is applicable worldwide for investigators, regulatory authorities, representatives in industry, policy makers, funders, and health-care professionals.

Lancet Oncol 2014; 15: e341–50

See **Online** for author interview with Jeremy Whelan

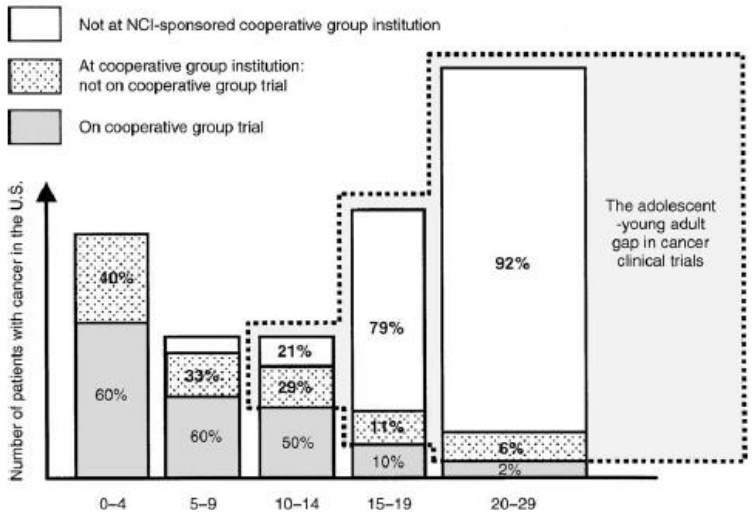
Department of Oncology, University College London Hospitals Foundation NHS Trust, London, UK (L A Fern PhD, Prof J Whelan MD); **National Cancer Research Institute Teenage and Young Adult Clinical Studies Group, London, UK** (L A Fern, Prof J Whelan); **and National Cancer Research Institute, London, UK** (J A Lewandowski MS, K M Coxon PhD)

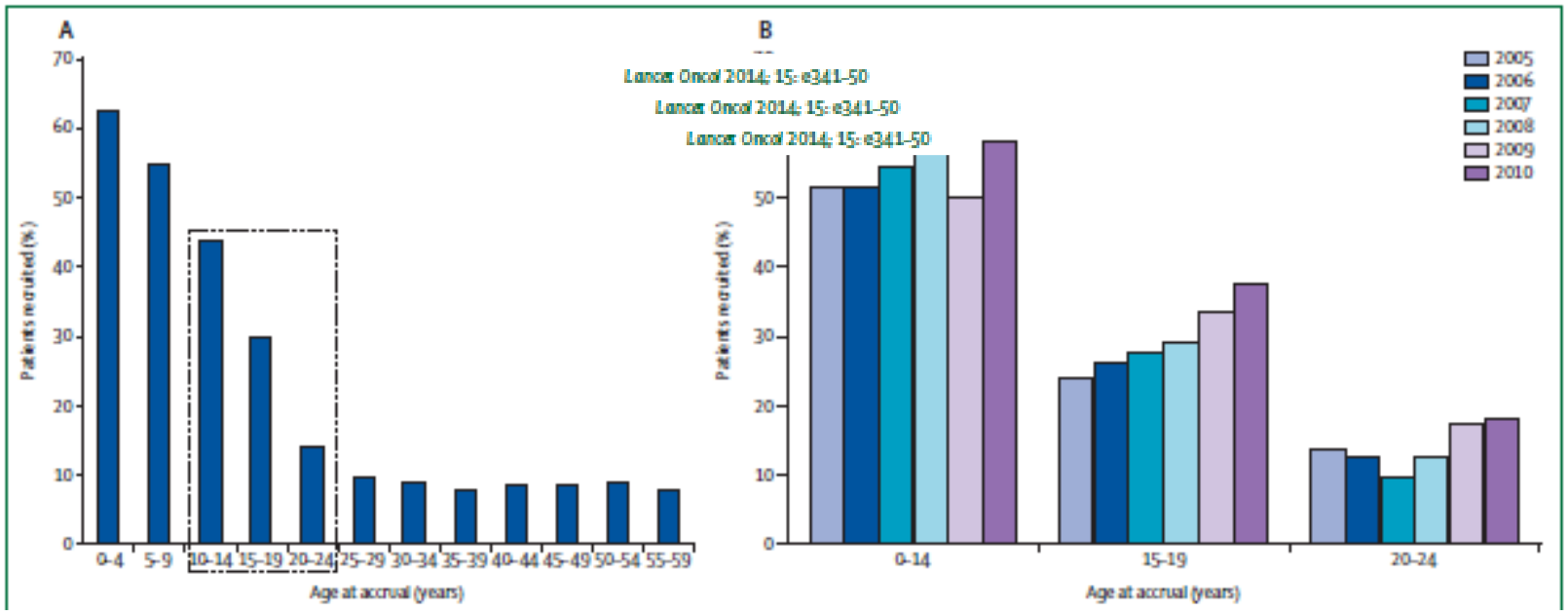
Correspondence to: Prof Jeremy Whelan, Department of Oncology, University College

Introduction

treatment protocols, and poorer rates of participation in

Albritton K, Bleyer W. Eur J Ca. 2003.





Lancet Oncol 2014; 15: e341–50

How I treat acute lymphoblastic leukemia in older adolescents and young adults

Emily Curran and Wendy Stock

University of Chicago Medicine and University of Chicago Comprehensive Cancer Center, Chicago, IL

The largest prospective study to evaluate the feasibility of a pediatric regimen in AYA ALL patients is the US intergroup study, C10403.[36] Between November 2007 and December 2012, 318 AYAs between 16 and 39 years of age were treated based on the standard arm of the Children's Oncology Group (COG) regimen (AALL0232).[37] This study demonstrated that toxicities were manageable, with low treatment-related mortality (3%), and that treatment with this pediatric regimen is feasible when administered by an adult hematologist/oncologist to an AYA population up to 40 years of age.[36] On this regimen, the 2-year EFS and OS were 66% and 78%, respectively.[34] Based on these very encouraging early results, the US cooperative groups are now designing a successor study using the C10403 platform that will attempt to incorporate novel targeted agents to further improve treatment outcomes.

Surveillance and survival among adolescents and young adults with cancer in Ontario, Canada

William Furlong[1], Charlene Rae[1], Mark L. Greenberg[2] and Ronald D Barr[3]

[1] Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Canada
[2] Pediatric Oncology Group of Ontario and University of Toronto, Toronto, Canada
[3] Department of Pediatrics, McMaster University and McMaster Children's Hospital, Hamilton, Canada

Gains in survival rates among adolescents and young adults (AYA) are reported from the USA to be lower than in both younger and older patients. Limiting factors include low accrual to clinical trials related to the type of institutional care. This study aimed to determine the incidence of cancer in the 15–29 age group in Ontario, and the 5-year survival of these cases by disease class, age at diagnosis group and highest level of institutional complexity of care. The primary data source was Cancer Care Ontario (CCO). Diseases were classified according to an AYA-specific system. Age at diagnosis was grouped as 15–19, 20–24 and 25–29 years; and institutional site of care was categorized as pediatric oncology group of Ontario (POGO) centers, regional cancer centers (RCC—tertiary care centers associated with CCO), RCC affiliate and satellite institutions and other institutions having no specialized cancer services. More than 10,000 incident cases were identified during 1990–2001. Carcinomas and lymphomas each accounted for >20% of the total. Overall 5-year survival rate was 83%; significantly higher for lymphomas at POGO centers and RCC than elsewhere. About 40% of eligible AYA cases were treated at a POGO center and 25% of those were accrued to clinical trials. The low proportion of adolescents referred to pediatric cancer centers may result in a survival disadvantage for this group. All AYA, especially with lymphomas, should be referred to specialized centers. Accrual of AYA to clinical trials must be improved substantially.

Int. J. Cancer: **131**, 2660–2667 (2012)

Developmentally Appropriate Care

- The Tasks of Adolescence
  - physical development, the formation of self-identity, school achievement, decisions about the future, the development of peer and sexual relationships, and achieving independence and autonomy from parents
  - A cancer diagnosis can prevent or disrupt the accomplishment of developmental tasks which are viewed as essential for transition into healthy adulthood.
- Thus affecting the AYA's health care
  - Adherence.
  - Peer influence can compete with demands of health care
  - Cognitive development – inconsistent thought processes, difficulty taking on other views, inability to reason and weigh things up, preoccupation with here and now, impulsivity, difficulty accepting cancer as part of identity.
  - Experimentation/risk taking behaviours

Developmental stage

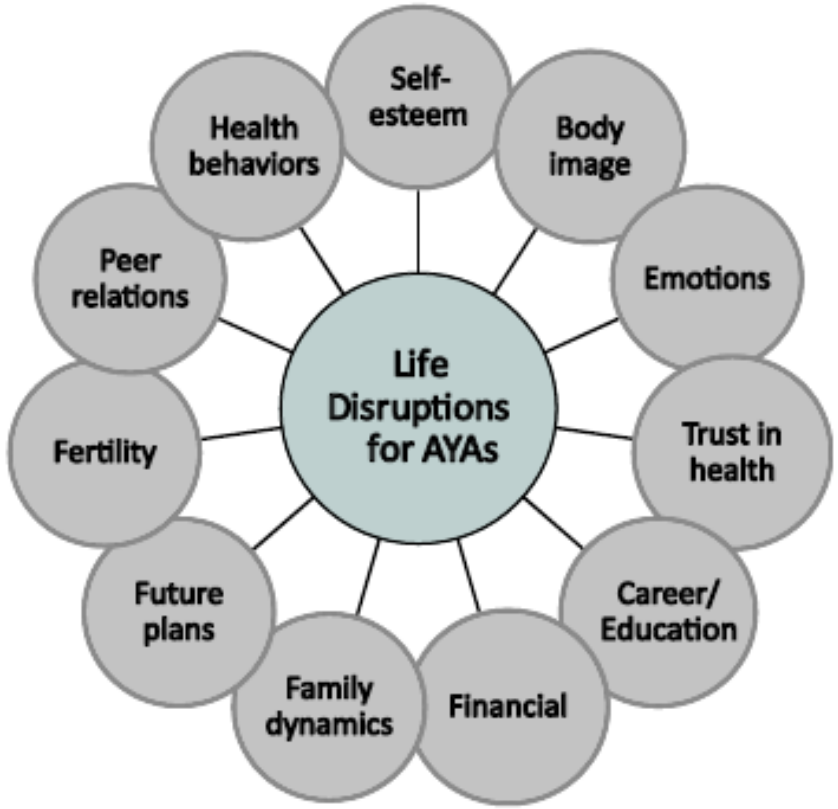
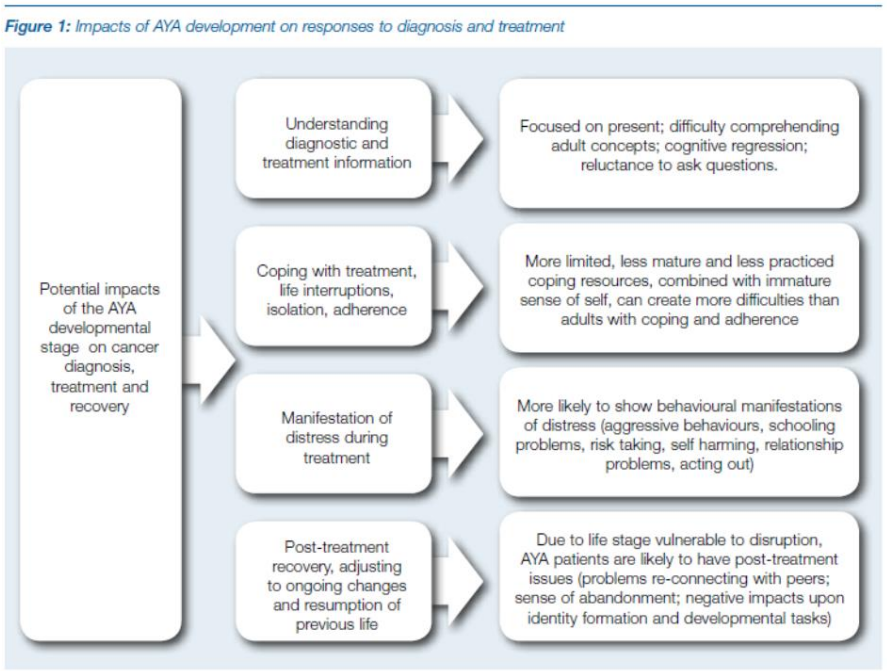


Figure 2. Possible life disruptions for AYA patients with cancer [5, 22]. Abbreviation: AYAs, adolescents and young adults.

The Oncologist 2015;20:186–195



Palmer. Cancer Forum. Vol 33 Number 1. Mar 2009.

Psycho-Oncology
Psycho-Oncology **24**: 1104–1115 (2015)
Published online 21 January 2015 in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.3730

Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer

Mindy C. DeRouen[1] Ashley Wilder Smith[2] Li Tao[1,3] Keith M. Bellizzi[4] Charles F. Lynch[5] Helen M. Parsons[6] Erin E. Kent[7] and Theresa H. M. Keegan[1,8]* for the AYA HOPE Study Collaborative Group[9]

Abstract

***Objective*: Adolescents and young adults (AYAs) diagnosed with cancer between 15 and 39 years of age often report need for greater amounts of cancer-related information and perceive that cancer has had a negative impact on control over their life. We examined whether unmet information need and perceived control over life are associated with health-related quality of life (HRQOL).**

***Methods*: We examined data from 484 AYA cancer survivors recruited from population-based cancer registries in 2007–2008. Participants completed surveys a median of 11 months after diagnosis. Multivariable linear regression analyses estimated associations of unmet cancer-related information needs and impact of cancer on control over life on HRQOL (SF-12).**

***Results*: Two-thirds of AYAs reported an intermediate or high level of unmet information need, and half (47%) reported a negative impact of cancer on control. Greater unmet information need was associated with lower overall mental and physical HRQOL and lower levels of all HRQOL subscales except vitality. A negative impact on control over life was associated with lower overall mental HRQOL as well as lower HRQOL across all subscales except general health perceptions (all $p < 0.05$). In multivariable analyses, perceived control and unmet information need were independently associated with HRQOL (p-values for interaction > 0.1).**

***Conclusions*: Adolescent and young adult patients with cancer have high levels of unmet cancer-related information needs and perceived negative impact of cancer on control over life; both were independently associated with lower HRQOL. Addressing unmet information needs among AYA cancer survivors and finding ways to increase their sense of control may help improve HRQOL in this understudied population.**

Allowing Adolescents and Young Adults to Plan Their End-of-Life Care

abstract

OBJECTIVE: The objective of this study was to assess and compare the usefulness, helpfulness, and stress associated with reviewing a previously adapted advance care planning guide, My Thoughts, My Wishes, My Voice, in comparison with the widely used adult document Five Wishes by adolescents and young adults (AYAs) living with a serious illness.

METHODS: Fifty-two participants (age 16–28) living with metastatic or recurrent cancer or HIV infection (acquired at birth or early in life) were presented pages randomly from My Thoughts, My Wishes, My Voice and, Five Wishes, and asked to rank 25 items on several factors, including how likely they would be to complete each statement. Participant opinion on suggested changes in content, design, format, and style was obtained and resulted in development of a new document.

RESULTS: AYAs living with a life-threatening illness want to be able to choose and record (1) the kind of medical treatment they want and do not want, (2) how they would liked to be cared for, (3) information for their family and friends to know, and (4) how they would like to be remembered.

CONCLUSIONS: AYA views of what should be included in an advance care planning guide were incorporated into a new document, Voicing My Choices, that provides youth, families and providers an opportunity to reduce the silence around the dying process by allowing an opportunity to share one's voice. We provide guidance on how to incorporate this tool into care. *Pediatrics* 2012;130:897–905

Service Provision for Adolescent and Young Adult Cancer Patients in New Zealand including Standards of Care

PROVISIONAL

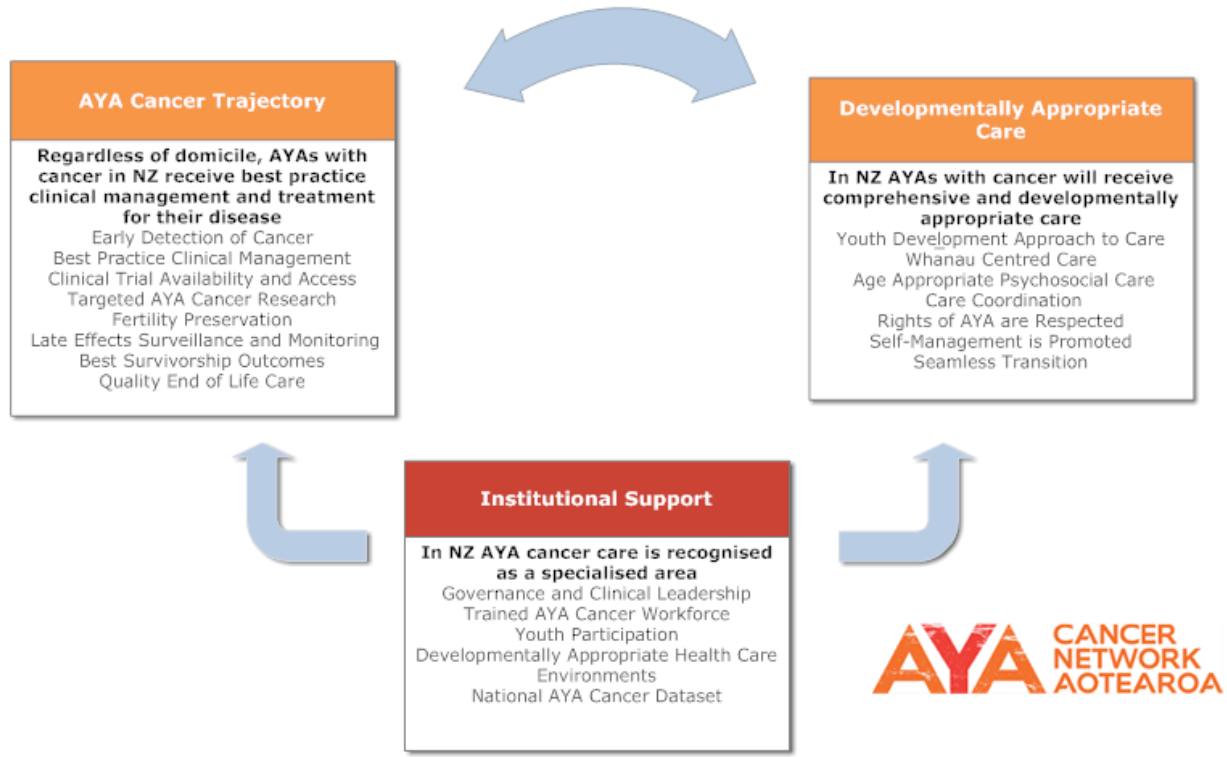
2016

AYA CANCER NETWORK AOTEAROA

ADVANCING CANCER CARE FOR 12-24 YEAR OLDS

Service Provision for Adolescents and Young Adult Cancer Patients in New Zealand

Aim: To achieve excellence in AYA cancer care in New Zealand with the goal of improving survival outcomes and supporting AYA's to transition to healthy functioning adults.



AYA CANCER NETWORK AOTEAROA

Section 1: The AYA Cancer Trajectory

Prevention and Early Identification

Standard 1.1 Cancer prevention education and interventions will be clearly communicated to AYAs, Whanau and Health Care Providers.

Standard 1.2 Early symptoms of cancer will be recognised by the AYA and health care provider to enable early detection.

Referral to the Right Expertise

Standard 2.1 When a cancer diagnosis is suspected, all AYA will be referred to the appropriate tumour group expertise and Multi-Disciplinary Meeting (MDM).

The Diagnostic Process

Standard 3.1 Investigations undertaken during the diagnostic stage will comply with best practice recommendations as described in the national tumour standards.

Standard 3.2 Sedation and other techniques to reduce procedural distress will be made available to all AYA cancer patients.

The Treatment Plan

Standard 4.1 All AYA cancer patients will have a documented treatment plan that adheres to best practice recommendations.

Standard 4.2 All AYA patients referred urgently with a high suspicion of cancer receive their first cancer treatment or other management within 42 days.

AYA Targeted Cancer Research

Standard 5.1 All AYA cancer patients will be offered the opportunity to participate in targeted AYA cancer research.

Standard 5.2 All AYA cancer patients will be offered the opportunity to enrol in available diagnostic and therapeutic clinical trials.

Fertility Preservation

Standard 6.1 Prior to treatment, all AYA cancer patients will be informed about the potential risks of treatment related infertility, and where appropriate, fertility preservation procedures completed.

End of Life Care

Standard 6.2 AYA cancer patients will have access to palliative care services. Where appropriate, access will start at diagnosis.

Survivorship

Standard 7.1 Following completion of treatment, all AYA cancer patients will have a structured follow up plan that focuses on the multifaceted health issues of survivorship.

Standard 7.2 All AYA cancer patients and relevant health care providers will be provided with an end of treatment summary document.

Section 2: Developmentally Appropriate Care

Psychosocial Assessment and Care

Standard 8.1 All AYA cancer patients will have a psychosocial assessment at diagnosis which will be updated at regular intervals to inform their care.

Standard 8.2 All AYA cancer patients will have access to psychological support from diagnosis.

Standard 8.3 The spiritual needs of AYA cancer patients and their Whanau are proactively considered and addressed along the cancer journey

Developmental Milestones

Standard 9.1 All AYA cancer patients receive support and care to optimise their normal developmental process continues throughout their cancer journey.

Caring for whanau, partners and the community

Standard 10.1 Whanau, partners and the support network of an AYA diagnosed with cancer will have their practical, cultural and emotional needs identified and assistance provided to address these..

AYA Cancer patients identified at risk of non-adherence

Standard 11.1 AYA cancer patients with risk factors associated with increased non-adherence are identified and prioritised for intensive case management.

Self-Management

Standard 12.1 All AYA cancer patients are supported to self-manage their own health care as they mature.

Standard 12.2 All AYA cancer patients and whanau are provided with developmentally appropriate cancer related information.

Transition

Standard 13.1 All AYA cancer patients will be supported as they transition across services.

Confidentiality/ Rights / Respect and Trust

Standard 14.1 The rights of the AYA cancer patient are respected. A key focus is to establish confidentiality and trust.

Care Co-ordination

Standard 15.1 All AYA cancer patients and whanau will be provided with access to a nominated health care professional who will co-ordinate their care.

Standard 15.2 All AYA cancer patients will have access to co-ordinated multidisciplinary and multiagency care

Section 3: Institutional Support

Governance and Clinical Leadership

Standard 16.1 There is a governance structure with identified clinical leadership that provides direction and oversight for AYA cancer care.

Work Force Development

Standard 17.1 Health care professionals and the supportive care workforce who work with AYA cancer patients are trained to deliver developmentally appropriate care.

Youth Participation

Standard 18.1 AYA cancer patients are provided with the opportunity to actively participate in the development, implementation and evaluation of regional and national AYA cancer care programmes and services.

Age Appropriate Environments

Standard 19.1 The AYA cancer patient will be treated in a health care environment that is developmentally appropriate.

Clinical Performance and Monitoring

Standard 20.1 A nationally agreed AYA cancer dataset will be collected within each DHB.

International Charter of Rights for Young people with Cancer

Delayed Diagnosis

- **Anecdotally- NZ young people diagnosed with solid tumors seem to be presenting with advanced or metastatic disease**

  Young People Report
  - **History of weight loss**
  - **Lethargy & tiredness**
  - **Ongoing pain**
  - **Repeated trips to the GP or different GP's**

Pediatr Blood Cancer 2013;60:605–610

Symptom Interval in Pediatric Patients With Solid Tumors: Adolescents Are at Greater Risk of Late Diagnosis

Laura Veneroni, MS,[1,2] Luigi Mariani, MD,[3] Salvatore Lo Vullo, BSc,[3] Francesca Favini, MD,[1] Serena Catania, MD,[1] Marco Vajna de Pava, MD,[1] Maura Massimino, MD,[1] and Andrea Ferrari, MD[1]*

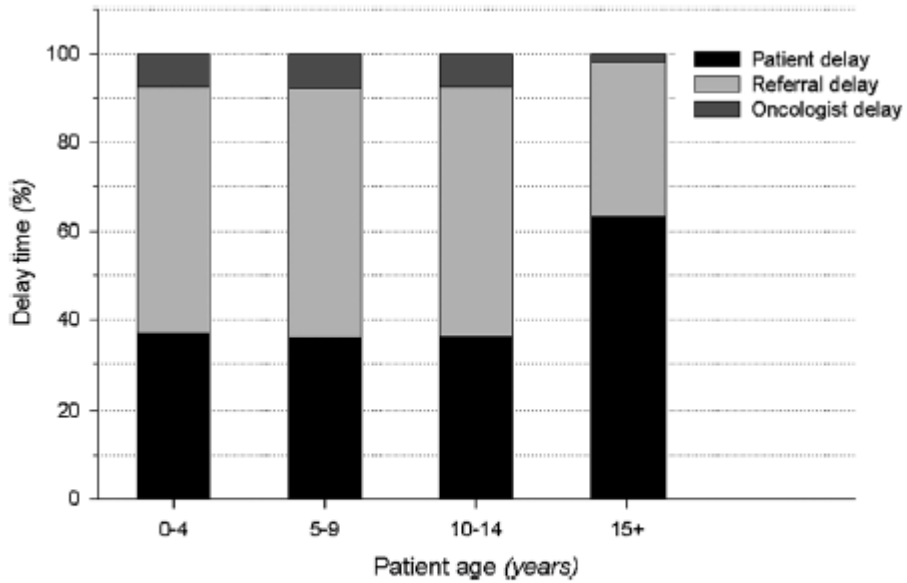


Fig. 2. A marked increase in the patient delay in terms of days relative to the overall symptom interval for the patients over 15 years of age.

The Symptom Interval in Children and Adolescents With Soft Tissue Sarcomas

Andrea Ferrari, MD[1]; Rosalba Miceli, PhD[2]; Michela Casanova, MD[1]; Cristina Meazza, MD[1]; Francesca Favini, MD[1]; Roberto Luksch, MD[1]; Serena Catania, MD[1]; Marco Fiore, MD[3]; Carlo Morosi, MD[4]; and Luigi Mariani, MD[2]

BACKGROUND: In a series of 575 patients ≤21 years of age with soft tissue sarcomas (STSs), the authors investigated the association patterns between symptom interval (ie, the period between the onset of the first symptoms or signs of the disease and its definitive diagnosis) and patient/tumor characteristics or disease outcome (in terms of survival). **METHODS:** The analysis was based on multivariate models (linear for associations with patient/tumor characteristics and Cox's for survival). **RESULTS:** The symptom interval ranged between 1 week and 60 months (median, 2 months) and tended to be longer the older the patient (ie, the interval was longer in adolescents than in children) and the larger the tumor's size, and for tumors located at the extremities and for nonrhabdomyosarcoma STSs (as opposed to rhabdomyosarcomas). A longer symptom interval unfavorably influenced survival ($P = .002$), which was also significantly affected by the patient's age and the size and surgical stage of the tumor. A different pattern of association between symptom interval and survival emerged for different types of STS histology. **CONCLUSIONS:** Our study points to an independent prognostic effect of symptom interval that cannot be explained by its associations with other factors, such as patient's age or the site, size, stage, and histology of the tumor. Future studies should focus more on the possible causes of symptom interval in pediatric STS populations to enable corrective measures to be implemented to reduce the diagnostic delay. *Cancer* **2010;116:177–83.** © *2010 American Cancer Society.*

At certain symptom interval time points, that is, 1, 12, and 24 months, the 5-year survival estimates were, respectively: 65.1% (95% CI, 51.1-76.1), 46.4% (95% CI, 28.1-63.6), and 19.7% (95% CI, 1.3-61.5) for RMS;

Niksic et al (2015).

- Young people aged 15-34 were the least likely to recognise the six common cancer symptoms.
- Young people most frequently identified barriers to attending GP appointments.

Kyle, Forbat & Hubbard (2012).

- One in four British adolescents could not recall a sign or symptom of cancer
- Lump or swelling had the largest recall (64.4%)
- All other symptoms had very poor rates of recall (< 14%)

- Emotional Barriers to seeking help were most endorsed
  - 'Worry about what the doctor will say' (71.8%)
  - 'Too embarrassed' (55.6%)
  - 'Not feeling confident to talk about symptoms (53.3%)

Research

Lorna A Fern, Christine Campbell, Tim OB Eden, Robert Grant, Ian Lewis, Una Macleod, David Weller and Jeremy Whelan

How frequently do young people with potential cancer symptoms present in primary care?

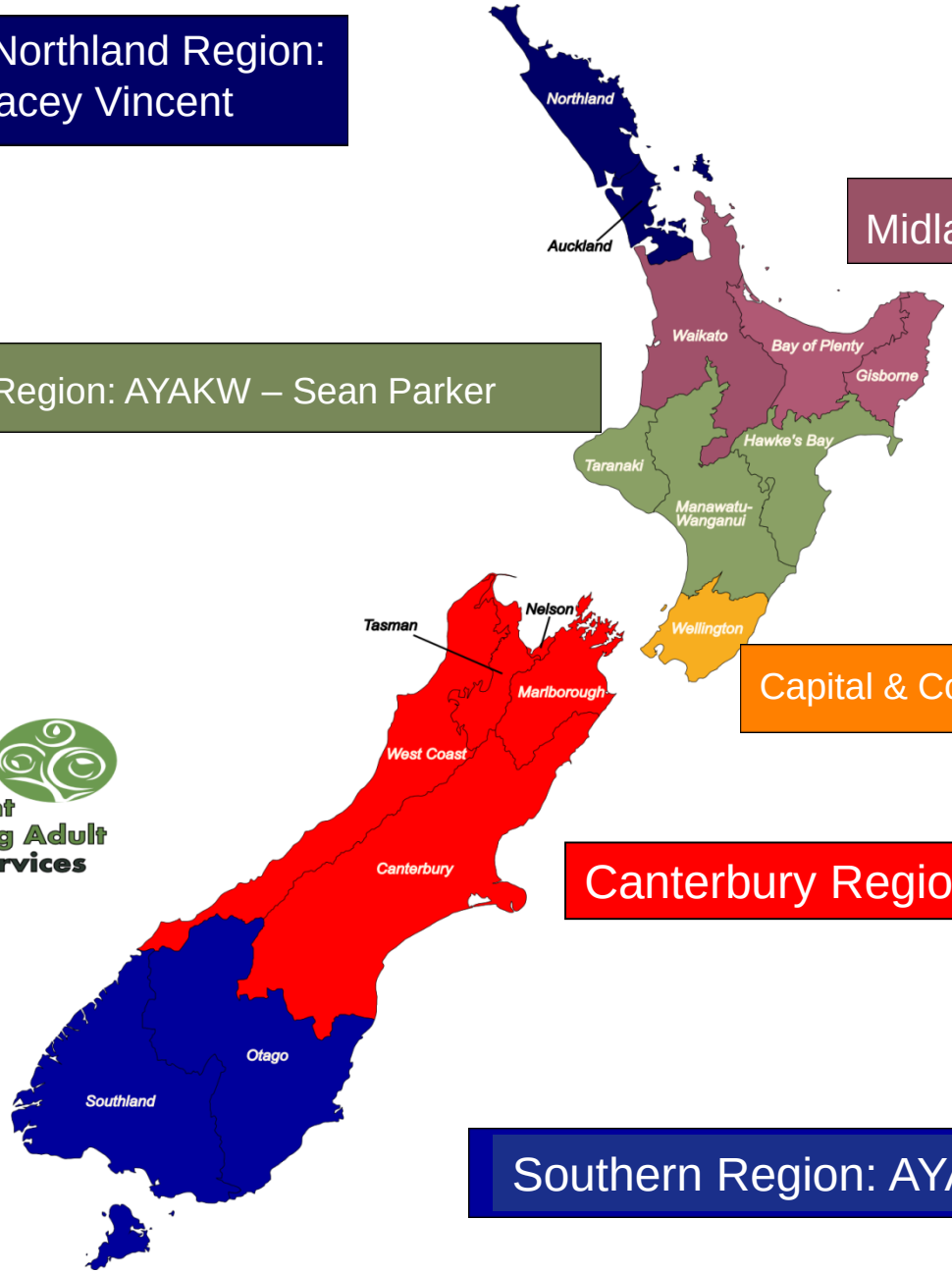
Table 4. Distribution of alert symptoms by sex and age

	Males, *n* (%)			Females, *n* (%)			Total, *n* (%)		
Alert symptom, *n*	15–19 years	20–24 years	15–24 years	15–19 years	20–24 years	15–24 years	15–19 years	20–24 years	15–24 years
Pain (all)	16 (32.7)	22 (43.1)	38 (38.0)	20 (31.7)	38 (33.6)	58 (33.0)	36 (32.1)	60 (36.6)	96 (34.8)
Fatigue/tiredness	6 (12.2)	2 (3.9)	8 (8.0)	8 (12.7)	24 (21.2)	32 (18.2)	14 (12.5)	26 (15.9)	40 (14.5)
Lumps (all)	11 (22.4)	7 (13.7)	18 (18.0)	9 (14.3)	10 (8.8)	19 (10.8)	20 (17.9)	17 (10.4)	37 (13.4)
Headache	4 (8.2)	6 (11.8)	10 (10.0)	3 (4.8)	9 (8.0)	12 (6.8)	7 (6.3)	15 (9.1)	22 (8.0)
Rectal bleeding	4 (8.2)	2 (3.9)	6 (6.0)	1 (1.6)	7 (6.2)	8 (4.5)	5 (4.5)	9 (5.5)	14 (5.1)
Pigmented lesion	0 (0.0)	4 (7.8)	4 (4.0)	4 (6.3)	1 (0.9)	5 (2.8)	4 (3.6)	5 (3.0)	9 (3.3)
Lymphadenopathy	0 (0.0)	1 (2.0)	1 (1.0)	4 (6.3)	2 (1.8)	6 (3.4)	4 (3.6)	3 (1.8)	7 (2.5)
Weight loss	2 (4.1)	0 (0.0)	2 (2.0)	3 (4.8)	1 (0.9)	4 (2.3)	5 (4.5)	1 (0.6)	6 (2.2)
Fainting	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	5 (4.4)	5 (2.8)	0 (0.0)	5 (3.0)	5 (1.8)
Post-coital bleed	0 (0.0)	0 (0.0)	0 (0.0)	2 (3.2)	3 (2.7)	5 (2.8)	2 (1.8)	3 (1.8)	5 (1.8)
Other	6 (12.2)	7 (13.7)	13 (13.0)	9 (14.3)	13 (11.5)	22 (12.5)	15 (13.4)	20 (12.2)	35 (12.7)
Total	49 (100.0)	51 (100.0)	100 (100.0)	63 (100.0)	113 (100.0)	176 (100.0)	112 (100.0)	164 (100.0)	276 (100.0)

Auckland & Northland Region:
AYAKW – Tracey Vincent

Midland Region: AYAKW – Ellyn Proffit

Mid-Central Region: AYAKW – Sean Parker



Capital & Coast Region: AYAKW – Liz Sommer

AYA
Adolescent and Young Adult Cancer Services

Canterbury Region: AYAKW – Louise Sue

Southern Region: AYAKW – Val Waugh

AYA Cancer Service Team

Dr Ruth Spearing
Haematologist
AYA Clinical Lead

Louise Sue CNS
AYA Cancer Key Worker

Dr Tristan Pettit
Paediatric Oncologist
AYA Standards of Care Chair

Dr Kate Gardner
Oncologist

Silas Thielmann
Social Worker

Dr Sean MacPherson
Haematologist

Rebecca Lee
Health Psychologist

Sarah Anticich
Clinical Psychologist

AYA South Island Supra-Regional MDT VC

Fortnightly on a Tuesday

0830 - 0915

- Venues: Oncology Whanau Room, Christchurch Hospital and University Paediatric room, Dunedin Hospital

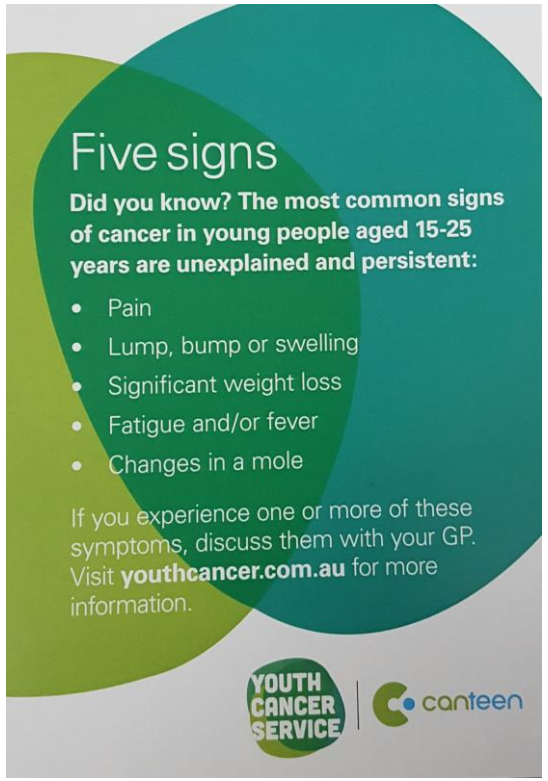
Agenda format:

0830: AYA service issues

0845: Patient discussion

The Service

- 12 – 24 year olds
- Virtual Service
- MDM’s – fortnightly
- Coordination
- Direct support/ psychosocial assessment and care
- Advocacy
- Liaising with NGO’s



Service Development

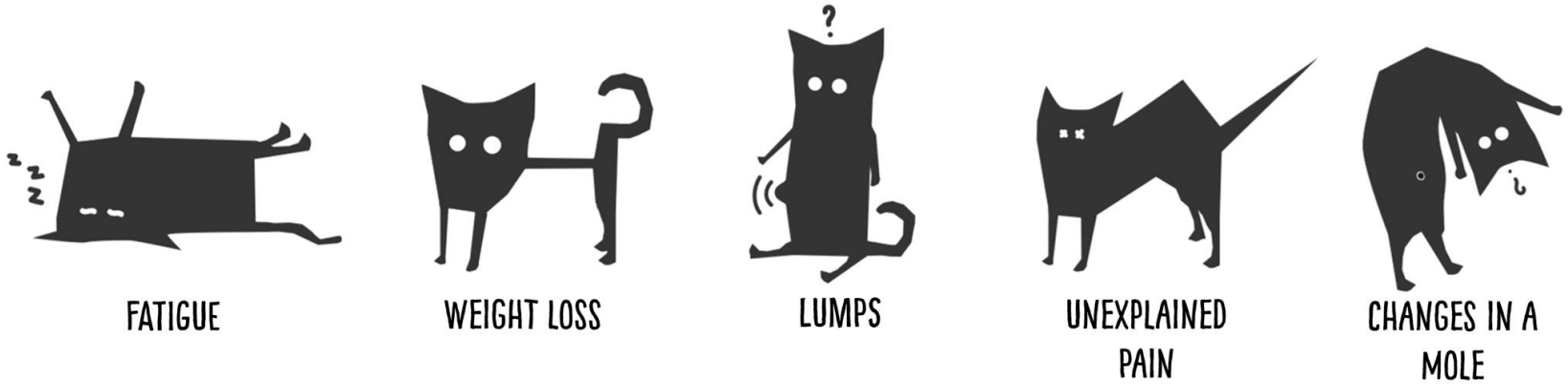
Aim to develop youth friendly resources, services and environments

AYA friendly environments

- Youth Inpatient room – ward 26
- Adolescent outpatient space – Interim CHOC
- AYA Cancer Unit – ASB

AYA friendly Resources

- YCS Psychosocial Screen
- Survivorship Passport
- AYA Cancer Website
- Insurance Pamphlet for AYA with cancer
- Voicing My Choices



Louise Sue
Adolescent & Young Adult Cancer Key Worker
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03 3641 541 or 0273826584

AYA
Adolescent
and Young Adult
Cancer Services