Sponsored session

Adolescents and Young Adults with Cancer: Why do they need our attention?

Organised by

Canadian Partnership Against Cancer

Partenariat Canadien Contre le Cancer
Addressing the Unmet Needs of Adolescents and Young Adults (AYA) with Cancer

PRESENTED BY:
Paul Grundy MD
Canadian Partnership Against Cancer

Congress Track #:  Track 3
Disclosure of interest:  None declared
Affiliated organisation:  Canadian Partnership Against Cancer
Objectives:

1. Describe what makes AYA cancer patients special

2. Identify some of the major issues in AYA cancer care
Who are AYA?

• AYAs with cancer:
  • age 0-14: about 1200 per year in Canada (~35m pop)
  • age 15-24: about 1200
  • age 15-29: about 2400
  • age 15-39: about 7600

• Definition is context dependent
Different Types of Cancer

FIGURE 1
Most common cancers by age

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Cancer Types</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–14*</td>
<td>Leukemia, Central nervous system, Lymphoma, Neuroblastoma and other peripheral nervous cell tumours</td>
</tr>
<tr>
<td>15–29</td>
<td>Thyroid, Testis, Hodgkin lymphoma, Melanoma, Bone &amp; soft tissue sarcoma, Non-Hodgkin lymphoma</td>
</tr>
<tr>
<td>30–39</td>
<td>Thyroid, Breast, Melanoma, Colorectal, Cervix, Testis</td>
</tr>
<tr>
<td>40+*</td>
<td>Lung, Colorectal, Breast, Prostate</td>
</tr>
</tbody>
</table>

*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.
5 year Survival increase by Age

Challenges for AYA

- Educational and career progress may be impaired by absenteeism, cognitive and physical complications.
- Normal psychosocial development such as forming and maintaining romantic relationships and attaining autonomy from one’s family may be substantially delayed.
- Serious chronic health problems after treatment, potential to lower quality of life and result in premature death.
Fertility and Sexuality – Mental Health

• Fertility and sexuality are major concerns for AYA
  • But often seen as low importance by health care providers

• Evidence suggests AYA want to know about fertility regardless of options

• AYA may suffer feelings of loss, compromised self esteem and identity

• Anxiety and depression are very common both during treatment and afterwards
Paucity of Research

• Few clinical trials address AYA-specific diseases/issues

• Accrual to trials that include AYA is poor

• AYA represent 4% of cancer patients: 0.4% research dollars focussed on AYA

• Little information available that specifically addresses issues/problems/survival for AYAs
Why do AYA Need our Attention?

- AYA survivors will live 50 to 60 years beyond their diagnosis and treatment
- Decreased productivity due to long-term complications or disabilities resulting from cancer treatment during formative years
- Long-term impact on negotiating education, launching careers, developing independence and forming adult relationships
- Personal, societal and socioeconomic impact is disproportionately greater than in older adults
- Population perhaps the least equipped to cope
Current State of AYA Cancer Care Globally

- Most countries are years behind the provision of specialized care for AYA with cancer compared with UK, Australia, New Zealand and others
- Lack of awareness of the needs of AYA
- No national vision
- Sporadic, small, isolated programs
- Poor clinical trial enrollment, availability of trials and research directed at improving outcomes
More Information


• http://www.virtualhospice.ca/
Thank you

FOR MORE INFORMATION:

Paul Grundy
Paul.Grundy@partnershipagainstcancer.ca
1-780-248-5408
The impact of advocacy, national coordination and professional development on access to oncofertility support for adolescent and young adult cancer patients

Dr. Antoinette Anazodo
Paediatric and Adolescent Oncologist
Sydney Youth Cancer Service
Risk of Infertility in Cancer Patients

- Fertility can be compromised by cancer diagnosis or cancer treatment:
  - Decreases the number of follicles that produce eggs or a decrease in the number of sperms
  - Interferes with the functioning of reproductive organs
  - Damage to the neuroendocrine pathways
  - Results in fertility related psychological distress
Fertility Preservation

• Fertility preservation is the umbrella term used for medical and surgical treatment to minimize the impact of cancer treatment on future fertility

• The burden of cancer related infertility affects 1 in 10 cancer patients of a reproductive age

• Infertility is a potential preventable public health problem which can have medical consequences

• The ability to easily preserve fertility prior to cancer treatment or after cancer treatment can provide hope for patients who want to have a family later in life
Oncofertility Care

- Oncofertility is a subfield that bridges cancer and reproductive disciplines to explore and expand options for the reproductive future of a cancer survivor.

- Oncofertility care also incorporates other aspects of reproductive care:
  - Family planning
  - Management of complex contraception
  - Hormonal management
  - Management of sexual dysfunction
  - Reproductive survivorship care
  - Psychological management
  - Practical support

It still makes me angry to think that I might have had time to collect eggs before I started my chemo if I was referred.
Access to Oncofertility Care

• <50% Patients are given information about infertility risk and fertility preservation options internationally

• 40% of survivors do not recall discussing the impact of treatment on fertility

• 43% cancer clinicians consider communication about fertility preservation difficult

• 23% of fertility preservation discussions are initiated by the patients

• 25% of cancer HCP’s consider communication about fertility preservation a burden

• 33% patients found communication either too fast, too late or unclear

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Youth Cancer Services are funded by the Australian Government and by state/territory health departments.

Referral Pathways

- Most centres have no policy on provisions of oncofertility care
- Referral pathways are usually unclear
- 50% of cancer clinicians are unaware of fertility preservation options for female patients
- Only 13% of cancer centres have a referral program
- A paper which examined referral sources showed that referrals are most often from academic centres (64%), followed by oncologists (28%) patients and parents (10%)

When I asked my cancer doctor to refer me to see a fertility doctor I was surprised that he was not sure who to refer me to.
Age Appropriate Care

- AYA patients showed high ratings of importance for information on treatment effects on fertility risk, fertility preservation and family planning discussions.
- AYA patients want detailed verbal and written information on options, risks, benefits, side effects and success rates of FP.
- Younger patients uncomfortable in the presence of parents
- Clinicians are wary of upsetting families while discussing FP
- AYA patients want information tailored to age, life stage, personal journey

My cancer doctor was so nervous and embarrassed talking about fertility preservation and sexual health that I could not ask any questions and I regret that now!
National Coordination and Consistency in Care

- Fertility identified as a key physical need in the National Service Delivery Framework (Cancer Australia and CanTeen Australia, 2008)

- Young people with cancer need to understand how cancer treatments may affect their fertility and how to maximise the potential preservation options

- When a treatment plan may threaten or affect patients future fertility, young people need to consult a fertility counsellor to explore their future fertility options
Fertility again highlighted as an important issue for AYA cancer care in the Australian Youth Cancer Framework in multiple instances:
1. The needs of young cancer patients
2. Principles of person and family centred care
National Coordination and Consistency in Care

• Information about access to fertility preservation identified as a key priority for action during phase 2 of the YCS program (2013-2017)

• Phase 2 KPI for fertility preservation = 65% of newly diagnosed patients must received written and/oral information about fertility preservation

• Quarterly activity data incorporating tracking of this KPI and other fertility related items provided to CanTeen by each of the 5 YCS teams and aggregated nationally
Monitoring Via Activity Data

• Activity data collected from the start of Phase 2 about the following data points:
  • Number of new patients provided with written and/or oral information on fertility preservation
  • Number of new patients who were referred to a fertility preservation specialist
  • Number of new patients who have undergone fertility preservation
Data Collected in Phase 2

- Discussion between CanTeen and YCS indicated the understanding the quantum of patients for whom fertility preservation was not relevant/appropriate.
- Understanding the quantum of patients who decline fertility preservation was also important.
- Two additional items added to quarterly activity data collection from July 2015:
  - Number of new patients where fertility preservation was not clinically relevant or appropriate.
  - Number of new patients that declined fertility preservation.
YCS National Professional Development

- All staff sessions – YCS Network Meetings in 2013, 2016
  - Includes coverage in primary care, medical legal, fertility preservation, nursing and sexual health perspectives
- Medical Practice Session – YCS National Meeting in 2014
- Coverage at 2015 Inaugural AYA Oncology Congress
- First Oncofertility Symposium 2017
- Clinical update session – YCS Community of Practice Meetings in 2018
- Updates and coverage in multiple YCS Matters newsletters
Efforts to Improve Uptake and Utilisation

- Development of resources
- Development of patient peer support
- Research studies occurring at same time
  - Australasian Oncofertility Registry, fertility related psychological distress, cultural competencies, models of care, competency frameworks, non-biological parenting options, cumulin bio-markers
- Joint applications for 7 new Medicare item numbers
- Training of health care professionals
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Activity Data - Information Provisions

- Sustained information provisions
- Consistent provision in excess of KPI (65%)

<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of newly diagnosed patients provided with written and/or oral information on fertility preservation</td>
<td>77%</td>
<td>75%</td>
<td>84%</td>
<td>74%</td>
<td>79%</td>
</tr>
</tbody>
</table>
Activity Data – Relevancy for Patients

- Relatively consistent proportion of patients for whom fertility preservation was judged to be not relevant
- Information helpful to inform us about service gaps

<table>
<thead>
<tr>
<th>Proportion of new patients where fertility preservation was not clinically relevant or appropriate</th>
<th>2015-16</th>
<th>2016-17</th>
<th>2017-18</th>
</tr>
</thead>
<tbody>
<tr>
<td>25.81%</td>
<td>26.52%</td>
<td>29.33%</td>
<td></td>
</tr>
</tbody>
</table>
### Activity Data – Decline Rates

- Decline rates difficult to capture removed after 2016/2017
- Relatively low but variable year to year

<table>
<thead>
<tr>
<th>Proportion of new patients that declined fertility preservation</th>
<th>2015-16</th>
<th>2016-17</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5.33%</td>
<td>11.89%</td>
</tr>
</tbody>
</table>
Activity Data – Referral Rates

- Consistent referral throughout phase 2
- Need to take into account those patients when fertility is not relevant

<table>
<thead>
<tr>
<th></th>
<th>2013-14</th>
<th>2014-15</th>
<th>2015-16</th>
<th>2016-17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of new patients who were referred to a fertility preservation specialist</td>
<td>47%</td>
<td>44%</td>
<td>38%</td>
<td>43%</td>
</tr>
<tr>
<td>Proportion of new patients who were referred to a fertility preservation specialist for whom fertility preservation was relevant</td>
<td></td>
<td></td>
<td>51%</td>
<td>58%</td>
</tr>
</tbody>
</table>
**Activity Data- Fertility Preservation Uptake**

- Significant increase in the number of patients who are having fertility preservation

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of new patients who have undergone fertility preservation</td>
<td>36%</td>
<td>28%</td>
<td>32%</td>
<td>35%</td>
<td>35%</td>
</tr>
<tr>
<td>Proportion of new patients who have undergone fertility preservation for whom fertility preservation was relevant</td>
<td></td>
<td></td>
<td>43%</td>
<td>48%</td>
<td>50%</td>
</tr>
</tbody>
</table>
Future Initiatives

• Focus on survivorship in phase 3 and so reproductive survivorship needs will be reviewed
• Implementation of competency framework to improve the uptake of international guidelines
• Tailored education to nurses/allied health professionals (ENRICH/ECHO)
• Use IT strategies to reach rural and regional patients as well as sick patients
• Complete Medicare process ensuring Australia has comprehensive public access for oncofertility care

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Conclusion

- Fertility risk and options important to AYA patients and patients want to hear about reproductive risk and options
- YCS has demonstrated a national approach to improve fertility preservation care
- Significant improvements in information provisions, referral and uptake of fertility preservation
- Further work is needed to ensure that all patients hear about reproductive risk at diagnosis and are provided with access to oncofertility care
Thank You

- YCS Staff across Australia
- CanTeen staff who have provided oversite and governance for Phase 2/3 initiatives.
National implementation of a distress screening protocol to identify risk and build resilience for adolescents and young adults with cancer

Pandora Patterson PhD
CanTeen Australia
University of Sydney
Outline

• Screening for Distress
• YCS and the AYA Oncology Psychosocial Care Manual
• The International Distress Thermometer (DT) study
  • Clinical Utility - Health Care Professionals
    • Australian Youth Cancer Service DT KPIs and monitoring data
  • Clinical Utility - AYA patients
• Service Responsiveness
Screening for Psychological Distress

- Assessment of psychosocial wellbeing of adolescent and young adults (AYAs) with cancer is vital to the provision of personalised support and care

- Responsive to individuals’ specific needs and concerns, and identifies individuals’ strengths as a means of building resilience.

- On the individual level, systematic screening across the cancer trajectory allows clinicians to monitor patients’ needs, concerns, and strengths adjusting care accordingly

- On the service level, monitoring unmet needs and distress across patients facilitates service provision planning.

Patterson, P., Hardman, F., Cheshire, J. & Sansom-Daly, U.M. (2018). Balancing risk with resilience: Using holistic screening and assessment tools effectively with adolescents and young adults with cancer. In P. R. Olsen & S. Smith (Eds.), Nursing Adolescents and Young Adults with Cancer: Developing knowledge, competence and best practice.

The Australian Youth Cancer Service

- The Australian Government provides funding to CanTeen to administer and manage the Australian YCS.

- Provides specialist multi-disciplinary medical and psychosocial treatment and care for AYA patients (15-25yrs) in five lead hospitals and a network of around 30 additional hospitals nationally.

- Commencing in 2010, the Youth Cancer Services now has an extensive national footprint, reaching 70 per cent of all newly diagnosed young Australian cancer patients.
AYA Oncology Psychosocial Care Pathway

Screening Tool
- Identify current distress
- Identify current needs
- Provide information
- Build rapport
- Highlight ongoing involvement
- Act on immediate need

Care Plan
- Develop plan
- Act on current need
- Establish rapport
- Identify referrals
- Create document for circulation
- Empower AYA patient

Assessment Measure
- Revise and refine Care Plan
- Develop in-depth understanding of patient
- Understand risk factors and protective factors
- Promote healthy survivorship

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Responsive to the idea of a national approach, keen to enhance cross-institutional data collection.

A well developed yet not validated AYA-specific measure would be of greater clinical usefulness than using a validated measure that was not appropriate for the age group.

Distress thermometer was the best quick measure for distress.

Supported regular psychosocial screening, and appreciated benefits of psychosocial support during treatment.

Use of a standardized AYA psychosocial screening tool and care plan would have improved the psychosocial care they received.

Saw the benefit of such tools highlighting issues to think about during treatment and in opening discussions about getting help.
## Adolescent and Young Adult Oncology Screening Tool

### 1. General Distress

How much distress have you been feeling over the past week? (Circle a number from 0 to 10)

<table>
<thead>
<tr>
<th>High Distress</th>
<th>No Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Areas of Concern Information Provision Care Plan Development Date Signatures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office Use Only:</td>
</tr>
<tr>
<td>Patient Name:</td>
</tr>
<tr>
<td>Date of Admission:</td>
</tr>
<tr>
<td>Date of Next Admission:</td>
</tr>
<tr>
<td>Information Provided:</td>
</tr>
<tr>
<td>Clinical: Medical and diagnosis</td>
</tr>
<tr>
<td>Support services:</td>
</tr>
<tr>
<td>Communicate tools:</td>
</tr>
<tr>
<td>Mental health services:</td>
</tr>
<tr>
<td>Education: Education and support services</td>
</tr>
<tr>
<td>Feelings and thoughts:</td>
</tr>
<tr>
<td>Care plan:</td>
</tr>
<tr>
<td>Development:</td>
</tr>
<tr>
<td>Date:</td>
</tr>
<tr>
<td>Signatures:</td>
</tr>
</tbody>
</table>

### 2. Specific Areas of Distress or Concern

In the boxes provided, please indicate which areas have been an issue for you over the past week.

#### Practical
- Housing or living arrangements
- Education
- Work or career
- Transport or parking
- Bills or finances
- Family
  - Father and/or Dad
  - Mother and/or mother(s)
  - Partner, boyfriend or girlfriend
  - Child(ren)
  - Other family members

#### Emotional
- Anger
- Sadness
- Feeling alone or isolated
- Anxiety or fear
- Guilt
- Boredom
- Frustration or tearing
- Extreme moodiness
- Feeling hopeless or hopeless
- Feeling confused
- Loss of meaning or purpose
- Loss of faith or spirituality

#### Social
- Lost from friends
- Missing important events
- Friends don’t understand
- Worry about trouble
- Missing doing the “normal stuff” with friends

#### Physical
- General appearance
- Hair loss
- Breathing difficulty
- Fitness or sport
- Sleep
- Fatigue
- Eating or appetite
- Extreme fatigue or tiredness
- Memory or concentration

#### Other areas of concern not listed:

---

I, ________________________________ understand that the above information will be used by my treating team to develop a care plan for me.

Patient Signature: ____________________________ Date: ____________

Clinician Signature: ____________________________ Date: ____________

☐ I am currently participating in a clinical trial or research study. Name of trial or study: ____________________________ Date: ____________
A national approach to improving adolescent and young adult (AYA) oncology psychosocial care: The development of AYA-specific psychosocial assessment and care tools

SUSAN PALMER, PH.D., 1 PANDORA PATTERSON, PH.D., 2 AND KATE THOMPSON, M.A.S.W. 3
1AYA Psychologist, Melbourne, Victoria, Australia
2CanTeen Australia, Sydney, New South Wales, Australia
3ONTrac at Peter Mac, Victorian Adolescent & Young Adult Cancer Service, Peter MacCallum Cancer, Melbourne, Victoria, Australia
International Distress Thermometer Study

Primary aims:
• determine appropriate cut-off for clinical use
• assess clinical utility
• confirm content validity of the checklist.

Validation of the distress thermometer for use among adolescents and young adults with cancer in Australia: a multicenter study protocol

Background: Adolescents and young adults (AYAs) diagnosed with cancer commonly experience elevated levels of distress. Routinely administered distress screening tools can be effective in identifying individuals in need of referral to psychosocial services. The distress thermometer and problem checklist are widely used screening tools that have been validated among some cancer populations, but which have not to date been validated for use among AYAs with cancer. The primary aim of this study is to validate the distress thermometer and a modified problem checklist for use with AYA cancer patients, aged 15–25 years. Specifically, we aim to 1) determine appropriate cutoffs for clinical referral on the distress thermometer; 2) investigate the content validity of the modified problem checklist; and 3) assess the clinical utility of the tool from the perspectives of both patients and health care professionals. The secondary aims of the study are to 4) establish prevalence and predictors of distress in AYA cancer patients and 5) examine the number and character (including uptake) of post-screening referrals made to psychosocial services.

Pandora Patterson, Fiona EJ McDonald, Antoinette Anazodo, Daniel SJ Costa, Claire EWakefield, Kate White, Kate Thompson, Michael P Osborn.

Research, Evaluation and Social Policy, CanTeen Australia, Sydney, NSW, Australia; & Cancer Nursing Research Unit, Sydney Nursing School, The University of Sydney, Sydney, NSW, Australia.
AYA Demographics (N = 105)

<table>
<thead>
<tr>
<th>Cancer type</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hodgkin lymphoma</td>
<td>24</td>
</tr>
<tr>
<td>Testicular germ cell carcinoma</td>
<td>13</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>12</td>
</tr>
<tr>
<td>Lymphoblastic leukemia</td>
<td>11</td>
</tr>
<tr>
<td>Ewing's sarcoma</td>
<td>8</td>
</tr>
<tr>
<td>Myeloid leukemia</td>
<td>6</td>
</tr>
<tr>
<td>Brain tumour</td>
<td>4</td>
</tr>
<tr>
<td>Rhabdomyosarcoma</td>
<td>4</td>
</tr>
<tr>
<td>Other leukemia</td>
<td>3</td>
</tr>
<tr>
<td>Colorectal carcinoma</td>
<td>2</td>
</tr>
<tr>
<td>Osteosarcoma</td>
<td>2</td>
</tr>
<tr>
<td>Other soft tissue sarcoma</td>
<td>2</td>
</tr>
<tr>
<td>Breast carcinoma</td>
<td>1</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1</td>
</tr>
<tr>
<td>Ovarian germ cell carcinoma</td>
<td>1</td>
</tr>
<tr>
<td>Other carcinoma</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>95</td>
</tr>
</tbody>
</table>

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# Distress Rates

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Sample</th>
<th>% distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patterson et al.</td>
<td>2018</td>
<td>Australian AYAs</td>
<td>56%</td>
</tr>
<tr>
<td>Chambers et al.</td>
<td>2014</td>
<td>Prostate Cancer: Age = 63.4</td>
<td>10%</td>
</tr>
<tr>
<td>Hegel et al.,</td>
<td>2008</td>
<td>Breast Cancer Age = 57.8</td>
<td>10%</td>
</tr>
<tr>
<td>van der Geest et</td>
<td>2017</td>
<td>Childhood Cancer Survivors</td>
<td>26%</td>
</tr>
<tr>
<td>Lynch et al.;</td>
<td>2011</td>
<td>Lung cancer; Age all over 56.</td>
<td>29%</td>
</tr>
<tr>
<td>Johnson et al.,</td>
<td>2017</td>
<td>Cancer Survivors; Age = 55.9 years</td>
<td>35%</td>
</tr>
<tr>
<td>Chan et al.</td>
<td>2018</td>
<td>Asian Adolescents Cancer Patients (Singapore)</td>
<td>43%</td>
</tr>
<tr>
<td>Sherry et al.,</td>
<td>2017</td>
<td>Metastatic Lung Cancer; Age = 65.7</td>
<td>45%</td>
</tr>
<tr>
<td>Loquai et al.</td>
<td>2013</td>
<td>Melanoma; Age = 58.5</td>
<td>47%</td>
</tr>
<tr>
<td>Mitchell</td>
<td>2007</td>
<td>Pooled Results From 38 Analyses</td>
<td>19% - 38%</td>
</tr>
</tbody>
</table>

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Clinical utility framework

- **Appropriateness**
  - Relevance and effectiveness of tool; fitting in to existing processes

- **Practicability**
  - Ease of instructions; relationship between tool and capability

- **Acceptability**
  - Satisfaction with the tool and process

---

### Clinical Utility: HCPs (N=33)

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently conduct distress screening</td>
<td>Yes</td>
<td>82.8</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>17.2</td>
</tr>
<tr>
<td>How frequently do you screen for distress?</td>
<td>Occasionally (approximately &lt; 50% of the time)</td>
<td>20.8</td>
</tr>
<tr>
<td></td>
<td>Sometimes (approximately 50% or more of the time)</td>
<td>54.1</td>
</tr>
<tr>
<td></td>
<td>Always/nearly always (approximately 90% or more of the time)</td>
<td>25</td>
</tr>
<tr>
<td>How DT is administered</td>
<td>I give it to the young person to complete on their own</td>
<td>60.6</td>
</tr>
<tr>
<td></td>
<td>I read the distress screening tool to the person</td>
<td>42.4</td>
</tr>
<tr>
<td></td>
<td>Over the internet on a video call</td>
<td>12.1</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>3</td>
</tr>
<tr>
<td>Do you use the DT/PCL?</td>
<td>Yes</td>
<td>91.7</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>8.3</td>
</tr>
</tbody>
</table>
Clinical Utility: HCPs

The DT/PCL was easy for me to interpret.

The DT/PCL covered issues that I thought were important for AYA.

I would be happy to administer the DT/PCL to future patients.

The DT/PCL quickly identified patient problems to me.

The DT/PCL helped communication and rapport with the patient.

The DT/PCL helped patients communicate their needs to me.

The DT/PCL helped me identify problems I may not have otherwise.

The DT/PCL helped patients receive appropriate follow-up.

The DT/PCL has improved patient care.

The DT/PCL helped me manage distress in patients.
### Clinical Utility: HCPs (Barriers)

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Not a Barrier</th>
<th>Unsure</th>
<th>Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients are too unwell or distressed to complete the screening tool</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients are unwilling or reluctant to discuss their distress</td>
<td></td>
<td></td>
<td></td>
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<td>Lack of time</td>
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<td>Lack of clarity about who is responsible for screening for distress</td>
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<td>Limited resources for patient referrals</td>
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<tr>
<td>Staff uncertainty about distress treatment options</td>
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<td>Staff believe that screening tools are not useful</td>
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<td>Staff uncertainty about how to identify distress</td>
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<tr>
<td>Staff are uncomfortable discussing distress with patients</td>
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<tr>
<td>Staff do not believe that interventions for distress are effective</td>
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Youth Cancer Services are funded by the Australian Government and by state / territory health departments.
75% of newly diagnosed patients to be screened using the distress thermometer.
Challenges and Actions

Challenges

- Key person risk
- Measure/screening acceptability
- Patient too sick/incapable

Actions

- Education and training
- Quarterly monitoring and discussion of progress against KPI with each service. Recent addition of data feedback to facilitate discussions, including projections of likely position by end of year and performance relative to historical data
- Validation study
Clinical Utility: AYA Patients (N = 105)

- The layout of the distress screening tool was clear
- The language in the distress screening tool was easy to understand
- The distress screening tool did not take too long to complete
- The distress screening tool covered issues that were relevant to me
- I would be happy to complete the distress screening tool again as part of my future care
- Completing the distress screening tool helped me to communicate my emotional needs to my medical care team
- I needed help to complete the distress screening tool
- I would have liked to have completed my distress screening tool in a more private location
- The distress screening tool covered issues that were relevant to me
- The distress screening tool did not take too long to complete
Additional DT/PCL Items

...the health system can be frustratingly slow but this isn't listed as a distress trigger

Are you optimistic about the outcome of your treatment?

More about relationships with medical team and understanding of how medical team works

Questions specifically on why I'm expressing certain emotions

AYAs: Are there any additional items for the PCL?

- No
- Yes
Service responsiveness

- Use of a screening tool
- Triage of service
- Quality treatments

Three components for effective distress screening programs

Referrals after distress screening


Service Responsiveness

- Medical care team made me aware that help was available if I needed it
- I used the services my medical team referred me to
- The referrals helped me deal with my cancer experience better
- Medical care team used the information from the distress screening to provide me with relevant information
- Comfortable talking to my medical team emotional and psychological needs
- I was given referrals that were useful to me
- I feel more comfortable seeking professional help for emotional and psychological needs

Youth Cancer Services are funded by the Australian Government and by state/territory health departments.
3rd Global Adolescent & Young Adult Cancer Congress

December 4 - 6, 2018
Sheraton on the Park, Sydney

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COSA Guidances

Psychosocial management of AYAs Diagnosed with Cancer: Guidance for Health Professionals

“It is recommended that all treating teams use the Adolescent and Young Adult Oncology Psychosocial Care Manual – a three step psychosocial care pathway that integrates an AYA specific Screening Tool, Care Plan and Assessment Measure.”

“At a minimum, it is recommended that administration of the Screening Tool occurs at: diagnosis, early treatment, six months post-diagnosis, and treatment completion.”
YCS Survivorship KPIs: Phase 3

- Completion of psychosocial survivorship screen
- Completion of a survivorship care plan (the AYA Oncology Psychosocial Survivorship Care Plan or other)
- Referral to community-based services/support

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Survivorship KPIs: Phase 3

- Completion of psychosocial survivorship assessment
- Completion of a survivorship care plan
- Referral to community-based services/support

Phase 3 - Year 1: Completion rates

- Target: 2017-18
- Target: 2018-19
- Target: 2019-20