Supplemental online content for:

**Are NCI Cancer Centers Providing Adolescents and Young Adults With Cancer Focused Clinical Services? A National Survey**

Katherine Daunov, MSN; Michael Daunov, DO; Kara Noskoff, BA; Hilary Gan, MA; Simon Davies, EdD; Megan Farrell, MA; Whitney Hadley, MA, MSW, LSW; Amelia Baffa, MSN; Jennifer Giesel, PhD; Rachel Egler, MD; Alex Y. Huang, MD, PhD; John J. Letterio, MD; and Richard T. Lee, MD

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eAppendix 1: National AYA Survey
eAppendix 1. National AYA Survey

This survey is the product of a partnership between the Case Comprehensive Cancer Center, University Hospitals Seidman Cancer Center, and Teen Cancer America (TCA). Results from this survey will help inform and demonstrate areas of growth and need for support and resources in your communities, thereby strengthening the care of our Adolescent & Young Adult (AYA) patients and the national AYA network.

The survey takes 10-15 minutes to complete and in appreciation of your time we are providing you with a $20 Amazon Gift Card sent to you within two business days of completion. The survey is due on 10/01/2020.

Thank you for being part of this community that is improving the lives of young adults with cancer.

Sincerely,
Richard T. Lee MD, Director and Associate Professor (Case Comprehensive Cancer Center)
Katherine Daunov CNP (University Hospitals Cleveland Medical Center Seidman Cancer Center)
Simon Davies (Teen Cancer America)

1. General Information:
To begin, please tell us a little about yourself and your institution:

1A: Please provide us with your name: 

1B: Please provide us with your contact information (email):

2. Please describe your institution:  
   ○ Community hospital  
   ○ Community hospital affiliated with an academic center  
   ○ Academic medical center  
   ○ Other (please comment in next section)

Comment:

3. Are you a:  
   AYA = Adolescent & Young Adult  
   ○ Cancer center director  
   ○ AYA Program Manager/Director  
   ○ AYA Nurse Navigator  
   ○ AYA Social Worker  
   ○ Other (please comment in next section)

Comment:
### eAppendix 1. National AYA Survey (cont.)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. What is your training/background?</td>
<td>Adult hematology/oncology, pediatric hematology/oncology, registered nurse, advanced practice nurse, masters in business administration, masters in social work, other (please comment in next section)</td>
</tr>
<tr>
<td>Comment:</td>
<td></td>
</tr>
<tr>
<td>5. How important is AYA oncology care to your institution?</td>
<td>Not at all important, low importance, moderate importance, important, very important</td>
</tr>
<tr>
<td><strong>AYA = Adolescent &amp; Young Adult</strong></td>
<td></td>
</tr>
<tr>
<td>6A. On average please estimate how many NEW patients between the ages of 15-39 years are seen at your institution in one month?</td>
<td>0-25, 25-50, 50-100, 100-200, 200-300, 300-500, &gt;500</td>
</tr>
<tr>
<td>6B. On average please estimate how many FOLLOW-UP patients between the ages of 15-39 years are seen in a month at your institution?</td>
<td>0-25, 25-50, 50-100, 100-200, 200-300, 300-500, &gt;500</td>
</tr>
<tr>
<td>7. Does your institution currently have an AYA-specific oncology program (dedicated providers or services for AYAs to receive developmentally appropriate oncology care)?</td>
<td>Yes, No, No, but plan to develop in the future, Not Sure</td>
</tr>
</tbody>
</table>
eAppendix 1. National AYA Survey (cont.)

II. AYA Oncology Program:

AYA Oncology Program:

If you answered YES to question 7 please tell us more about your institution’s AYA Oncology Program

8. Approximately how many years has your institution’s AYA program been in existence?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- >10
### eAppendix 1. National AYA Survey (cont.)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>9A. What is the minimal age range of your institution’s AYA program?</td>
<td>10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50</td>
</tr>
<tr>
<td>9B. What is the maximum age range of your institution’s AYA program?</td>
<td>10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50</td>
</tr>
<tr>
<td>10. Is your institution’s AYA program embedded in adult or pediatric oncology or both?</td>
<td>Adult, Pediatric, Both, Unsure, Other (please comment in next section)</td>
</tr>
</tbody>
</table>
eAppendix 1. National AYA Survey (cont.)

Comment:

11. Are your institution’s AYA supportive services open to all patients with all types of cancers?
   - Yes - Select disease types in next section
   - No
   - Unsure
   - Other (please comment in next section)

Please indicate the types of cancers your institution’s AYA program treats:
   - Breast
   - Gastrointestinal
   - Genitourinary
   - Head and Neck
   - Hematologic
   - Lung
   - Sarcoma
   - Other cancers (melanoma etc...)

Comment:

12. Are your institution’s AYA oncology services provided for patients on treatment, off treatment, or both?
   - On treatment
   - Off treatment in survivorship
   - Both
   - Unsure
   - Other (please comment in next section)

Comment:

13. Where does your institution provide AYA services: (check all that apply)
   - Outpatient clinic at main campus
   - Outpatient clinic at satellite or affiliate center
   - Dedicated inpatient AYA oncology service
   - Inpatient consultation services for AYA patients admitted to hospital
   - Other (please comment in next section)

Comment:

14. Does your institution have dedicated physical spaces for AYAs?
   - Dedicated inpatient AYA lounge
   - Dedicated outpatient AYA lounge
   - Dedicated inpatient unit
   - Dedicated outpatient clinic space
   - Unsure
   - Other (please comment in next section)

Comment:

15. Does your institution have an AYA oncology patient advisory committee?
   - Yes
   - No
   - Unsure
   - Other (please comment in next section)
eAppendix 1. National AYA Survey (cont.)

16. Does your institution host AYA oncology patient peer social events?
   - Yes (please select frequency of events below)
   - No
   - Unsure
   - Other (please comment in next section)

   Comment:

Please choose frequency of AYA events:
   - Weekly
   - Monthly
   - Annually

17. Does your institution have a method to connect AYA oncology patients with peer to peer mentorship (resource for connecting patients one on one with a cancer survivor who has a shared experience)?
   - Yes
   - No
   - Unsure
   - Other (please comment in next section)

   Comment:

18. Does your institution have an AYA program website, social media, or other online platform? (please check all that apply)
   - AYA website (please provide URL)
   - Social media platforms for AYAs (facebook/twitter/instagram etc..)
   - No
   - Unsure
   - Other (please comment in next section)

   Comment:
**eAppendix 1. National AYA Survey (cont.)**

19. Which of the following services are available at your institution for cancer patients but not specifically dedicated to AYAs. (If not available, please check whether you would be interested in providing these services by checking "not available but interested")

<table>
<thead>
<tr>
<th>Service</th>
<th>YES</th>
<th>NO</th>
<th>NOT AVAILABLE BUT INTERESTED</th>
<th>NOT SURE</th>
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</thead>
<tbody>
<tr>
<td>Pediatric oncologists</td>
<td></td>
<td></td>
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<tr>
<td>Medical oncologists</td>
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<tr>
<td>Nurse/Patient navigators or case coordinator</td>
<td></td>
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<tr>
<td>Oncology survivorship provider(s)</td>
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<tr>
<td>Supportive oncology or palliative care services</td>
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<tr>
<td>Integrative oncology consultation (guidance about complementary therapies such as acupuncture, meditation and supplements)</td>
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<tr>
<td>Psychologist or psychiatrist</td>
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<tr>
<td>Sexual health/wellness providers</td>
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<tr>
<td>Social work</td>
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<tr>
<td>Child life specialist</td>
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<td></td>
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<tr>
<td>Financial services</td>
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<tr>
<td>Insurance counseling</td>
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<tr>
<td>Academic support services (tutor, scholarship resources, school reintegration resources/guidance, application resources)</td>
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<tr>
<td>Career resources (interview prep, resume resources, career fair, legal resources for job reintegration)</td>
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<tr>
<td>Physical therapy</td>
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<tr>
<td>Dietician/Nutrition therapists</td>
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<tr>
<td>Spiritual care/chaplain services</td>
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<tr>
<td>Art therapy</td>
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<tr>
<td>Music therapy</td>
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<tr>
<td>Acupuncture services</td>
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<td></td>
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<tr>
<td>Yoga therapy</td>
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<tr>
<td>Meditation/Mindfulness training</td>
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</tbody>
</table>
20. In contrast to Q19, please specify the full-time equivalents (FTE) for each position listed who have a portion of their job (time and/or funding) dedicated to service the AYA cancer patients.

<table>
<thead>
<tr>
<th>Provider Role Full-Time Equivalents</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXAMPLE: Director 0.5</td>
</tr>
<tr>
<td>Social Worker</td>
</tr>
<tr>
<td>Music Therapist</td>
</tr>
<tr>
<td>AYA Medical Provider</td>
</tr>
<tr>
<td>Advanced Practice Provider</td>
</tr>
<tr>
<td>Nurse who helps coordinate or manage patient care (a.k.a. Nurse/Patient Navigator or Program Nurse/Case Coordinator)</td>
</tr>
<tr>
<td>AYA Program Manager/Coordinator</td>
</tr>
<tr>
<td>Medical Oncologist</td>
</tr>
<tr>
<td>Pediatric Oncologist</td>
</tr>
<tr>
<td>Child Life Specialist/AYA Life Specialist</td>
</tr>
<tr>
<td>Psychologist</td>
</tr>
<tr>
<td>Psychiatrist</td>
</tr>
<tr>
<td>Administrative support</td>
</tr>
<tr>
<td>Research Coordinator</td>
</tr>
<tr>
<td>Nutritionist</td>
</tr>
<tr>
<td>Physical Therapist</td>
</tr>
<tr>
<td>Chaplain</td>
</tr>
<tr>
<td>Yoga Therapist</td>
</tr>
<tr>
<td>Integrative oncology consultation (guidance about complementary therapies such as acupuncture, meditation and supplements)</td>
</tr>
</tbody>
</table>
### III. Services at your Institution:

**The following questions are related to fertility preservation and sexual health at your institution:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 21. In general, how is fertility preservation discussed or brought up at your institution? (please check all that apply) | - Offered at diagnosis regardless of risk  
- Offered based on risk stratification according to planned oncologic treatment  
- Offered upon request  
- Documentation of discussion is mandatory in our EMR (hard stop for those of childbearing potential)  
- Not currently being offered  
- Unsure | |

**Comment:**

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<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 22. Who currently provides fertility preservation education and/or counsels patients? (please check all that apply) | - Oncology provider  
- Nurse practitioner  
- Nurse/Patient navigator  
- Reproductive endocrinologist/fertility specialist  
- Social worker  
- Community partner  
- Unsure  
- Other (please comment in next section) | |

**Comment:**

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<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 23. In general, when is sexual health of oncology patients addressed and managed at your institution? (please check all that apply) | - Included in part of routine assessment of patient  
- Addressed during survivorship  
- Discussed/Addressed upon patient request or reporting of sexual health symptoms  
- Patient education materials are available  
- Unsure | |

**Comment:**

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<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 24. In general, who addresses sexual health of oncology patients at your institution? (please check all that apply) | - Primary oncology team  
- Provided via a referral to male/female sexual health provider  
- Unsure  
- Other (please comment in next section) | |

**Comment:**

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<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 25. Does your institution have an LGBTQ (lesbian, gay, bisexual, transgender, and queer) dedicated clinic or services? | - Yes  
- No  
- Unsure | |
### eAppendix 1. National AYA Survey (cont.)

**Please tell us more about your institution’s oncology survivorship services:**

| 26. When are AYAs referred to survivorship clinic or services at your institution? | □ At the completion of treatment  
| | □ 1 year after completion of therapy  
| | □ 2 years after completion of therapy  
| | □ 3-5 years after completion of therapy  
| | □ 5 or more years after completion of therapy  
| | □ Other (please comment in next section)  
| | □ Not currently offered  
| | □ Unsure  

Comment:


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| 27. What types of services are provided for AYAs seen in survivorship? (Please check all that apply) | □ Dedicated cancer survivorship clinic  
| | □ Peer survivorship support group  
| | □ Transitional/Survivorship care plan or care path  
| | □ Academic support/school reintegration programming  
| | □ Other (please comment in next section)  
| | □ Not currently offered  
| | □ Unsure  

Comment:


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### eAppendix 1. National AYA Survey (cont.)

#### These next questions relate to ongoing academic research at your institution:

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. Is your institution affiliated with a national research consortium for oncology clinical trials?</td>
<td>Yes, No, Unsure</td>
</tr>
<tr>
<td>29A. What type of clinical trials do AYA oncology patients (15-39 years of age) have access to at your institution? (check all that apply)</td>
<td>Pediatric phase I trials, Pediatric phase II trials, Pediatric phase III trials, Adult phase I trials, Adult phase II trials, Adult phase III studies, Unsure, Other (please comment in next section)</td>
</tr>
<tr>
<td>Comment:</td>
<td></td>
</tr>
<tr>
<td>29B. Is there collaboration between pediatric and adult cancer researchers at your institution?</td>
<td>Yes -- please explain below, No, Unsure, Other (please comment in next section)</td>
</tr>
<tr>
<td>Comment:</td>
<td></td>
</tr>
<tr>
<td>30. What type of researchers do you have at your institution who are focused on or conducting AYA-specific research?</td>
<td>Clinical research, Psycho-social research, Health outcomes research, Translational research, Unsure, Other (please comment in next section)</td>
</tr>
<tr>
<td>Comment:</td>
<td></td>
</tr>
</tbody>
</table>
eAppendix 1. National AYA Survey (cont.)

<table>
<thead>
<tr>
<th>The following questions relate to ongoing education for healthcare providers and staff at your institution who may be involved in the care of AYA oncology patients.</th>
</tr>
</thead>
</table>
| 31. Does your institution currently have a method for training staff (nurses, pediatric/medical residents, fellows, nurse practitioners, and/or attending physicians) about providing developmentally appropriate care for AYAs or other topics related to AYA cancer care? | ○ Yes, please comment below  
○ No  
○ Unsure |

Please comment the type of programs that your institution offers:

______________________________________________________________________________

| 32. Is your institution providing or hosting an AYA oncology conference or educational program in the next 12 months? | ○ Yes, (If yes please describe below. Please state how frequently you have these events/programs)  
○ No  
○ Unsure |

Comment:

______________________________________________________________________________
eAppendix 1. National AYA Survey (cont.)

<table>
<thead>
<tr>
<th>33. Who provides symptom management services for AYA patients at your institution? Please select provider AND location</th>
</tr>
</thead>
<tbody>
<tr>
<td>We offer this service</td>
</tr>
<tr>
<td>Pediatric palliative/supportive oncology providers</td>
</tr>
<tr>
<td>Adult palliative/supportive oncology providers</td>
</tr>
<tr>
<td>Dedicated AYA palliative/supportive oncology</td>
</tr>
<tr>
<td>Anesthesia pain or interventional pain management specialists</td>
</tr>
</tbody>
</table>

Comment:

34. What resources (if any) are provided to AYAs and their families to assist with medical decision-making, goals of care, advanced care directives, and/or end-of-life care? (select all that apply)

- Palliative/Supportive oncology team
- Social work
- AYA advanced care planning resource (eg, Voice My Choices or Five Wishes)
- Psychologist/Psychiatrist
- Legacy work and memory making
- Grief support/counseling
- None offered
- Other (please comment in next section)

Comment:

35. Does your institution require documentation of advanced care planning/medical decision-making/code status?

- Yes
- No
- Unsure
- Other (please comment in next section)

Comment:
36. For the following question, please choose how well you feel your institution addresses AYA Oncology Care Services

- Sexual health of AYAs with cancer
- Addressing fertility in AYAs with cancer
- Survivorship care of AYAs with cancer
- Psychosocial needs of AYAs with cancer
- Research (clinical trials for AYAs; eg, clinical, psychosocial, health outcomes, translational)
- Education of medical/nursing/supportive staff about AYA development and cancer care
- Symptom management of AYAs with cancer
- End-of-life care of AYAs with cancer

37. Would you like to participate in our monthly AYA oncology educational webinar designed for medical and allied health professionals called “The Monthly Drip”?

- Yes
- No thank you
- I am already a participant

38. What is the best way for patients and providers who may want to refer to your program to access your institution’s services? List contact person, telephone, and website.

39. Please list any hospitals your institution is affiliated with for patient care:
eAppendix 1. National AYA Survey (cont.)

Thank you for taking the time to complete our survey. If you have any additional comments, or things you'd like to share with us about your institution's AYA oncology program or about your institution in general please feel free to provide it in the space below.

Open feedback

_________________________________________