



# ADOLESCENT AND YOUNG ADULT CANCER PRIORITY SETTING PARTNERSHIP



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**#AYACancerPSP**

*To join the mailing list or submit to the next newsletter,  
email Brianna Henry at [brianna.henry@ucalgary.ca](mailto:brianna.henry@ucalgary.ca)*

# ***A Message from the Co-Leads***

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***Perri Tutelman, PhD***



***Chantale Thurston***



***Fiona Schulte, PhD***

It has been a busy and productive summer for the Adolescent and Young Adult (AYA) Cancer Priority Setting Partnership (PSP)! We are excited to share key updates with the community in the second edition of our newsletter.

In this edition of the newsletter you will find an announcement of research funding, information on the launch of our main ([www.AYACancerPSP.ca](http://www.AYACancerPSP.ca)) website and James Lind Alliance Web page (<http://tinyurl.com/JLA-PSP>), and updates on initiatives in the broader AYA cancer community.

We are also getting ready to launch the first online survey to gather the perspectives of Canadian AYA cancer patients, caregivers, survivors, and clinicians about what they want answered by research. More information on the survey will be coming VERY soon!

Thank you for your support of the AYA Cancer PSP!

Perri, Chantale & Fiona  
AYA Cancer PSP Co-Leads

# Where We're At

1

## **Create Steering Group**

Composed of equal representation of patients, caregivers, and clinicians.  
\*The first Steering Group meeting was held on April 18, 2023.



2

## **Survey #1: Gather Evidence Uncertainties**

Patients, caregivers, and clinicians will respond to a survey that asks what questions they want answered by research.

**COMING  
SOON!**

3

## **Summarize Responses Gathered**

All survey responses will be sorted and summary questions will be created. This is the long list of questions.

4

## **Evidence Checking**

The long list of questions is checked against existing research evidence. Any questions that have been answered will be removed.

5

## **Survey #2: Interim Priority Setting**

To reduce the remaining long list, patients, caregivers, and clinicians will vote on the most important questions. This is the short list of questions.

6

## **Final Workshop**

The highest ranked 25-30 questions are discussed. Patients, caregivers, and clinics agree the "Top 10" list of priorities.

7

## **Dissemination**

The Top 10 is announced.

## **Successful Canadian Institutes of Health Research (CIHR) Grant**



We are thrilled to share that AYA Cancer PSP project leads Dr. Perri Tutelman, Dr. Fiona Schulte, Chantale Thurston along with Co-Investigators (Dr. Sara Beattie, Dr. Jacqueline Bender, Dr. Kathryn Birnie, Dr. Sheila Garland, Dr. Lindsay Jibb, Dr. Melanie Noel & Dr. Sapna Oberoi) received a Planning and Dissemination Grant from the Canadian Institutes of Health Research in the amount of \$25,000. The grant entitled: *A Priority Setting Partnership to Establish a Patient, Caregiver, and Clinician-Identified Research Agenda for Adolescents and Young Adults Cancer in Canada* will support the AYA Cancer PSP activities.

## Our Project Websites are LIVE!

### Project Website Live



Our project website provides additional information and updates on the AYA Cancer PSP.

- Learn about the project
- Meet the Steering Group, Partners, & Research Team
- Latest news
- Opportunities to get involved

Visit [www.AYACancerPSP.ca](http://www.AYACancerPSP.ca)

### James Lind Alliance Page Live

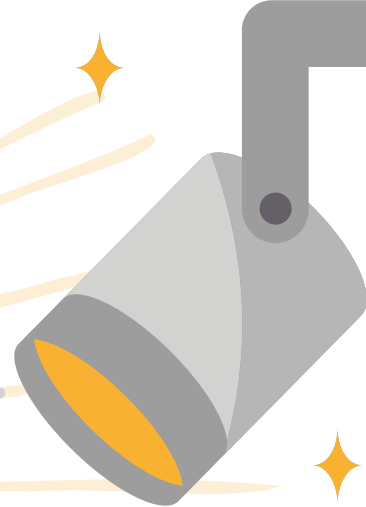


Each JLA PSP has a dedicated webpage on the JLA website. Ours is now live! Check it out to:

- Learn about the JLA and PSP process
- Protocol & Terms of Reference

Visit [tinyurl.com/JLA-PSP](http://tinyurl.com/JLA-PSP)

# COMING SOON!



Soon the AYA Cancer PSP will be launching the first survey in the process to determine the top 10 research priorities for AYA cancer in Canada.

We will be asking patients, caregivers, and clinicians what they would like to see answered by research, so that future studies can address what matters most to the community.

***STAY TUNED FOR THE LAUNCH!***

# *Upcoming Journal Special Issue on AYA Cancer*

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## **Current Oncology Special Issue**

**Guest Editors: Dr. Fiona Schulte (AYA PSP Co-Lead) & Dr. Cheryl Heykoop (AYA PSP Steering Group Member)**

This special issue aims to showcase research, community-based programs, partnerships, and policy and practice change initiatives that meaningfully engaged patients to understand their unique needs and strengthen AYA cancer care, support, and research. In doing so, we also seek to highlight efforts in AYA cancer care, support, and research that strengthen representation of diverse AYAs and their intersectional identities, perspectives and cancer experiences, and to advocate for more equitable cancer care and support for all AYAs.

Suggested manuscript topics include, but are not limited to:

- Patient-oriented research;
- Participatory action research;
- Patient engagement;
- Peer navigation;
- Systems transformation;
- Patient-clinician partnerships;
- Patient-centered care;
- Equity-oriented cancer care;
- Peer support;
- AYA navigator;
- AYA clinical programming;
- AYA support.

Deadline for Manuscript Submissions: September 30, 2023

For more information, visit: [tinyurl.com/COnc-Issue](https://tinyurl.com/COnc-Issue)



## **AYA CAN AUGUST COMMUNITY CALL**



AYA Can's next Community Call is Friday, September 8 at 1pm EST. Tune in for updates and short presentations for the AYA Community in Canada.

Check out our website for details at [www.ayacan.ca](http://www.ayacan.ca)