



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*

Happy Holidays

WARM WISHES FOR A HAPPY HOLIDAY SEASON

FROM THE AYA CANCER PSP TEAM



A Message from the Co-Leads



Perri Tutelman, PhD



Chantale Thurston



Fiona Schulte, PhD

It has been an exciting few months for the AYA Cancer PSP! This fall we launched the initial PSP survey, which is a significant milestone in the James Lind Alliance priority setting process. With support from the AYA community, we received over 300 responses to the survey from AYAs, their loved ones, and clinicians from across Canada!

Our next steps are now to summarize the research questions that were submitted and check them against the existing research evidence to determine which questions have not yet been answered by research. Those questions will move forward to a second survey, which will launch in 2024. Stay tuned for more information.

The AYA Cancer PSP is an initiative that is for the community, by the community. It would not be possible without your input and support! As we approach the holiday season, please accept our warmest wishes and appreciation.

We are looking forward to what 2024 has in store!

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.



**SURVEY
CLOSED!**

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.

INITIAL SURVEY NOW CLOSED!

Thank you!

**For taking part in the initial
AYA Cancer Priority Setting
Partnership survey**



We received over 300 responses!



**Stay tuned for next steps as we work
together to establish the Top 10 research
priorities for AYA cancer in Canada**

Upcoming Journal Special Issue on AYA Cancer

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.

Updated deadline for Manuscript Submissions: March 31, 2024

For more information, visit: tinyurl.com/COnc-Issue

AYA CAN FEBRUARY COMMUNITY CALL



AYA Can's next Community Call is Monday, February 12 (time TBD). Tune in for updates and short presentations for the AYA Community in Canada.

Check out their website for details at www.ayacan.ca

QUEERING CANCER SURVEY



All we want for Christmas is **100 survey responses! Please help us reach the target...🎯**

We are seeking responses from:

- ❤️ People with lived experience of cancer from the 2SLGBTQ+ community
- 🧡 Their caregivers
- 💛 Any oncology-focussed healthcare professionals
- 💚 Representatives from cancer support organizations
- 💙 Researchers & academics
- 💜 Allies & friends

Your responses will help guide our priorities over the next couple of years & ensure what we do is informed by our community ✨

🔗 Find the survey ➔ bit.ly/QCeval