

# Persons With Lived Experience (PWLE) Travel Subsidy

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## Goal:

- The PWLE Subsidy was included in the original CIHR grant application and is intended to provide ACCESS' PWLE's and/or their representatives with funding to attend short-term training and conferences to further their knowledge of childhood cancer and advocacy skills, and to bring back that knowledge to the PWLE Network to share with others who might benefit from the information, too.
- Some PWLE's would be unable to attend these workshops, conferences, etc without funding, and lack of funding is a barrier to participation of equity, diversity and inclusion (EDI) groups.

## Results:

The following are some of the expected results:

- Increased participation and presence of PWLEs at national and international pediatric oncology conferences and meetings
- Shared learning across the PWLE network (this is a requirement of successful applicants and they must include a plan to share the knowledge in their application)
- PWLEs better equipped to be effective childhood cancer advocates



"Thank you so much for the opportunity to attend SIOP... it was one of the most impactful events I've attended as a PWLE [and researcher]....On a personal note, this SIOP congress will always hold special meaning for me. My partner and I met years ago when we were both campers at Campfire Circle (Camp Oochigeas), as she is also a childhood cancer survivor. We've been together forever, navigating residual treatment effects and establishing ourselves as survivors. After the congress, we extended our stay and got engaged. I've attached a few photos we took to celebrate the moment. Thank you again for the opportunity and for the chance to contribute to the work ACCESS does. Warmly, CM"  
~ Childhood cancer survivor & researcher



EH attended the LFS Symposium in 2024 and participated on the Youth Panel with other youth affected by LFS. A video was produced as a knowledge translation output.  
~ AYA with Inherited/genetic predisposition

"Aftercare for young survivors is extensive as our aggressive treatments carry long-term impacts and late effects throughout our entire lifetime. During survivorship, we often only learn this vast information bit by bit as various challenges arise. This can cause a great deal of worry and uncertainty about our futures and what to expect" - VR, AYA Childhood Cancer Survivor and Advocate

## Objective:

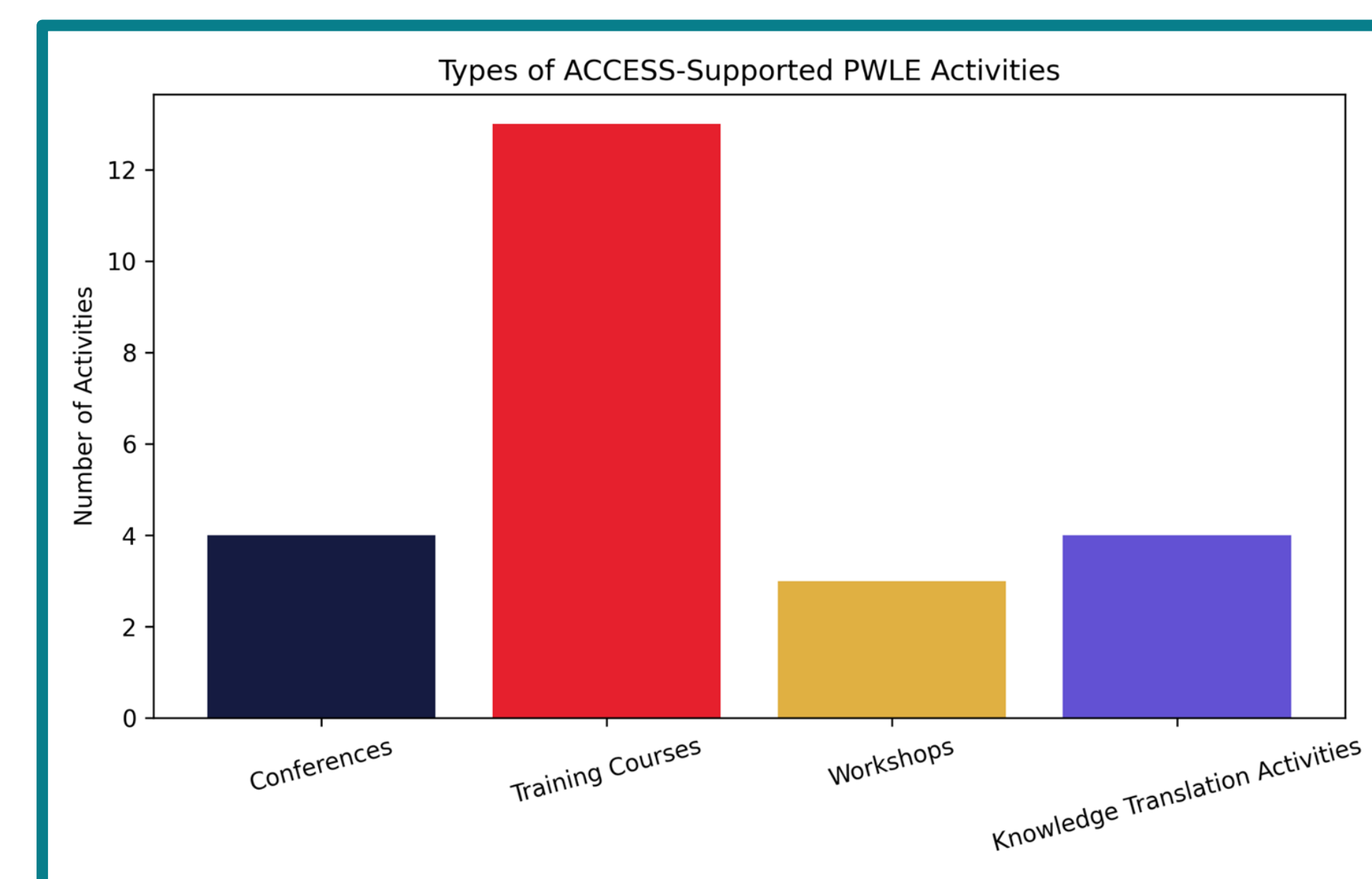
- As per the original CIHR Grant Application and the approved Matrix 5 Education and Training Budget, ACCESS will provide Persons With Lived Experience (PWLE) Subsidies for participation in short courses and national conferences and associated transportation, accommodations and meal stipends.
- As per the Budget in the original application there is \$107,500 over 2 years or \$53,750/year earmarked for this project.
- Aim 1 of Theme 5 is to "Improve patient involvement in pediatric cancer care and research". One of the key deliverables to do this is enabling PWLE attendance in training and conferences.

## Impact - Outcomes:

- Most PWLEs would be unable to attend these without funding, and lack of funding is a barrier to participation of EDI groups.
- 29 Applications received
- 9 declined or incomplete
- 20 subsidies have been given to date for PWLEs from 4 provinces/territories
  - 3 in 2024
  - 17 in 2025
- ACCESS has enabled the attendance of PWLEs at 4 conferences, 13 participatory training courses, 3 workshops, etc.
- 4 Knowledge Translation activities completed by recipients including:
  - Social media posts with quotes and impact stories
  - Presentations to ACCESS or ACCESS PWLE Network
  - Videos of participants engaging at the event

## Project Timelines:

- 2024:
  - Proposal submitted and accepted
  - Development of policies, templates, and communications
  - Launch and begin accepting applications
- 2025:
  - Identified key conferences to have ACCESS PWLE representatives attend
  - Promoted key conferences
  - Reviewed grant applications and informed recipients
  - Followed-up on knowledge translation commitments from recipients
  - Identified opportunities for streamlining the application and reimbursement claim processes
- 2026 (to-date):
  - Identified key conferences to have ACCESS PWLE representatives attend



## Study Method:

- This proposal included policy guidance, forms and a request to access the funds to accept and fund applications.
- The following are some expected deliverables from this initiative:
  - 10 patient partners/advocates per year will be sponsored to attend national conferences/meetings
  - 5 patient partners/advocates per year will be sponsored to attend international conferences/meetings
  - 5 patient advocates per year will be sponsored to participate in patient advocacy training opportunities
  - Learning from these opportunities to be shared with the larger PWLE Network and across ACCESS Themes and committees (e.g. presentations, blogs, social media posts shared with the help of ACCESS Communications staff, etc.)
- As noted in the Policies and Procedures, intake will be rolling, with applications submitted anytime and reviewed as quickly as possible. The review committee will be convened as needed and made up of 3 or more ACCESS representatives **including at least**:
  - 1 - Theme 5 Co-Lead (currently including Dawn Pickering, Chiquita Hessels, Meera Rayar and Laura Wheaton);
  - 1 - ACCESS staff member; and
  - 1 - Other PWLE volunteer (who does not have an application being considered).
- A matrix was developed and is used to rate applications to assist with decision making
- Successful applicants will be asked to give feedback on the value of their attendance and whether ACCESS should consider funding applicants for the opportunity again in future (after their attendance as part of their travel claim)
- After careful consideration, Theme 5 has decided to collect socio-demographic data to ensure equity, diversity and inclusion (EDI), and has done this in keeping with the ACCESS' recommended practice. Applicants may opt out of including this data if they prefer. If after Year 1 the data indicates that EDI efforts have been ineffective in attracting diverse applicants, ACCESS may choose to promote this more actively to increase participation in Year 2.



DP participated in an international meeting of patient partners and researchers of Anaplastic Large Cell Lymphoma (ALCL) in June 2025 to mount an international study of a rare cancer with a small population. She views ALCL cells through a microscope in the lab at Cambridge University as part of the tour.  
~ Parent/Caregiver of child with rare cancer, Dedicated Advocate

"Attending the SIOP 2025 Congress in Amsterdam as both a parent with lived experience and a nurse was a profound professional and personal milestone. I am deeply grateful for the opportunity to attend—an opportunity made possible through the support of ACCESS. Being present at an international forum where pediatric oncology research, clinical care, and health system priorities are actively shaped allowed me to engage fully with emerging evidence while carrying the perspective of a parent who understands the long-term impact of childhood cancer on families" JC, Parent, Nurse, Advocate

