UHN Research

Engaging People with Lived Experience in Research

PiPER | Pride in Patient Engagement in Research

November 21, 2025

Introduction to PLEX

Person with lived experience (PLEX)

A **PLEX** is a person with direct experience of a health condition or interactions with the health care system. They may be a current or former:

- Patient
- Family member
- Caregiver

Other terms you may also hear to describe a PLEX include patient partner, consumer, or knowledge user.

PLEX Engagement in Research

also known as *patient-oriented research or public involvement,* is the active, meaningful, and collaborative interaction between PLEX and scientists across all stages of the research and innovation process (plan, do, and share). Decision-making is guided by PLEXs' contributions as partners, recognizing their experiences, perspectives, priorities, and expertise.

The term PLEX Engagement does not mean:

- PLEX as **study participants**
- PLEX engagement in **quality improvement initiatives**

The Value of PLEX Engagement

To improve relevance, quality and outcomes

To improve responsiveness and alignment of research and innovation with the experiences, preferences, needs, and concerns of PLEX

To align with research best practices and increase grant success rate

Granting agencies are routinely requiring PLEX engagement and involvement.

CIHR IRSC
Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Canadian Cancer Society | Société canadienne du cancer

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PLEX Roles

PLEX can play FIVE roles.
Find role-specific training resources in the PiPER Toolkit.

ROLE	SUMMARY OF RESPONSIBILITIES
Team Members	Can perform roles as members of a team alongside scientists, innovators, development teams, clinicians, students, and research staff, among others.
Knowledge Ambassadors	Can help create, communicate, and share materials and information about a project/product and its results for a number of audiences.
Peer Reviewers	Can play a role in reviewing research and products, providing feedback, and evaluating future or past research activities based on their lived experiences and insights.
Decision Makers	Can play a role in shared decision making with development teams, scientists, clinicians, and staff members when overseeing the activities of a organization or initiative.
Fundraising Ambassadors	Can play a role in fundraising.

PLEX Roles in Action: Bare Bones Podcast

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Engagement Process & Compensation

Steering Committee Member

Decision Maker

PLEX Engagement Timeline

- Relationship building with PLEX
- Discuss project expectations and types of engagement
- PLEX role established
- PLEX CIHR Biosketch or Applicant CV
- Letter of Support (optional)
- Inform PLEX of decision period
- Funding received
- Notify PLEX and meet with team (1 hr)
- On-boarding training (1 hr)
- 6 meetings (1 hr each)
- Project activities (3 hrs)
- Off-boarding evaluation surveys (1 hr)

Research Planning | **Grant Decision Period** | **Research Cycle**

Grant Development | **Grant Cycle** | **Post-Grant Cycle**

CANTRAIN

- Seek opportunities to support PLEX (e.g., PiPER Grants, CANTRAIN Grants)
- Create Budget
- Set up method and frequency of payment
- Compensate PLEX for duration of engagement
  Expected cost for example above:
  $36/hr x 12 hrs = $432
- Reimburse if needed (e.g., travel accommodations, conference fees, etc.)

Budget Timeline

Feedback on today's roadshow:

https://www.surveymonkey.com/r/PIPERroadshow

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