

Partnering with Youth and Parents on Your Pediatric Research Grants: From Conceptualization to Submission

Andrea Chow & Maureen Smith

Trainee Hub | Edwin S.H. Leong Centre for Healthy Children, University of Toronto

April 22, 2025



uOttawa



INFORM
RARE

Overview



1

Introduction / learning objectives

2

Patient engagement: a definition

3

Trivia game!



4

Patient engagement at every stage

Learning Objectives



Identify the ways in which youth and families can contribute to developing your project ideas



Define the ways that youth and families can be reflected as members of the research team on a grant application

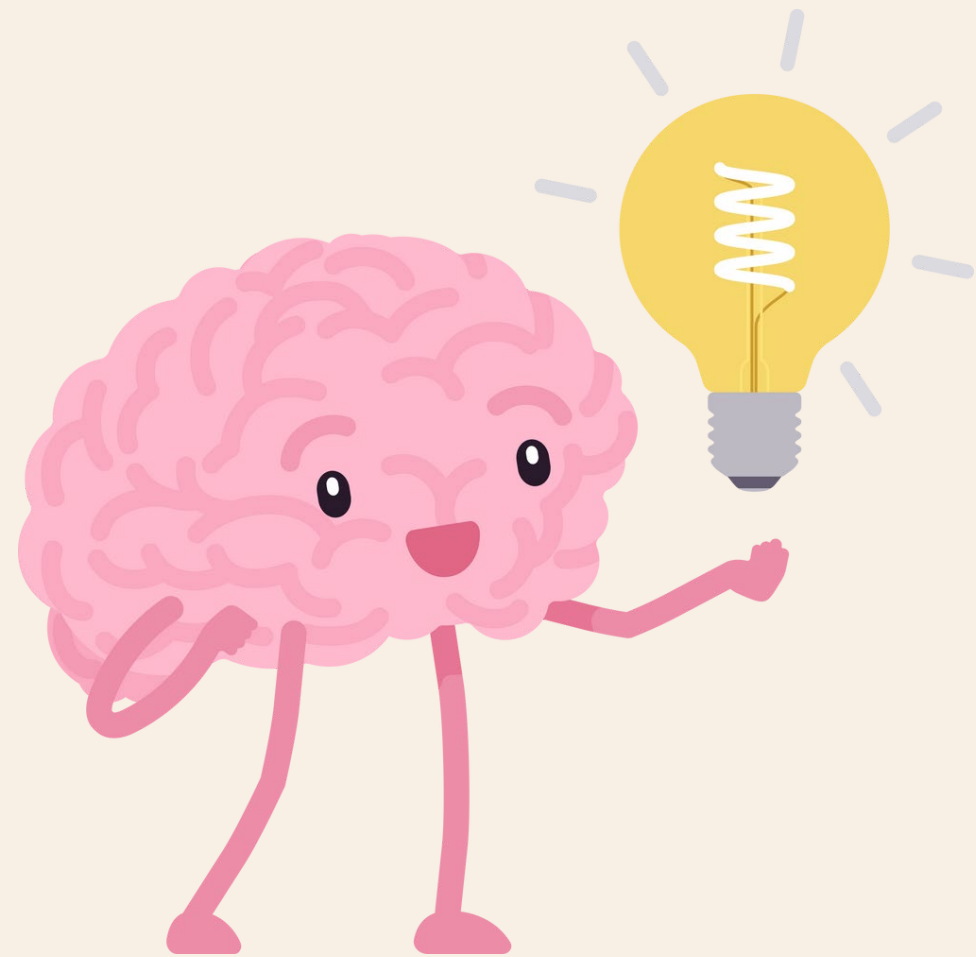


Identify the challenges and barriers to youth and families in fulfilling grant application requirements and potential approaches to supporting patient partners



Describe the considerations specific to developing grant applications for researchers working with youth and family partners from groups who are frequently under-served by, and challenged to participate equitably in, health research

What do we mean by patient engagement?



CIHR definition of patient partner

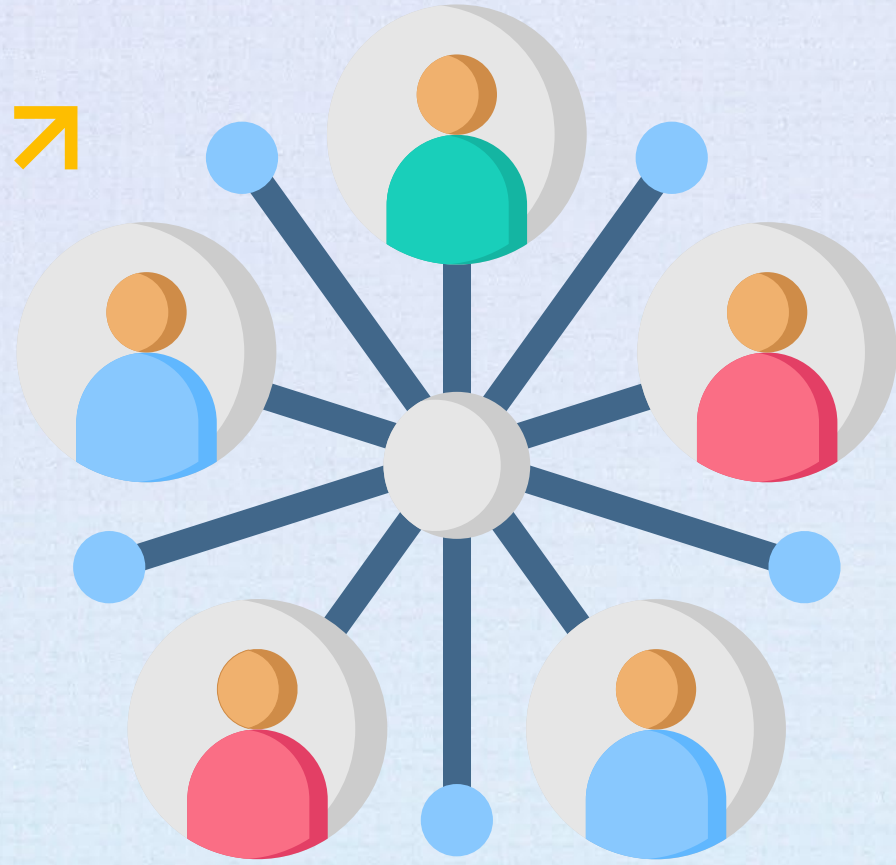
CIHR defines a "patient partner" as an overarching term encompassing individuals with lived experience of a health condition, including patients, caregivers, family, and friends.



What is patient partnered research?

- CIHR definition: “patient partner” describes when patients contribute to the research process and research -related activities, different from the traditional, more passive role, as research participant
- Involved in conducting research activities, **at all stages** of the research process, including supporting grant applications, assisting with participant recruitment and performing research dissemination activities





What's the big deal about *Patient Engagement*



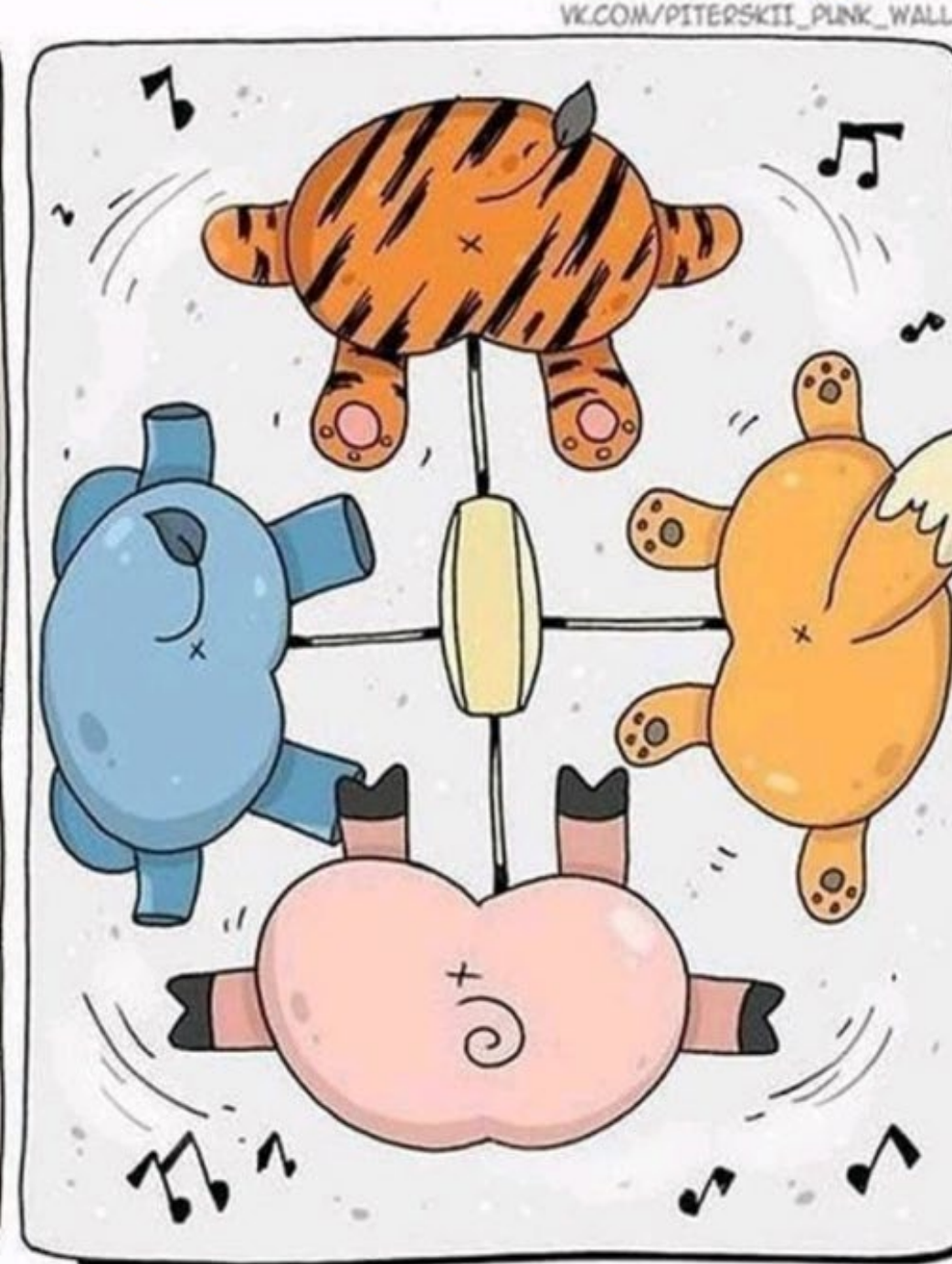
Who is better placed to understand the impacts, challenges, and realities of a condition than patients, families, and caregivers?

Why do patient engagement?

Researchers



Patients

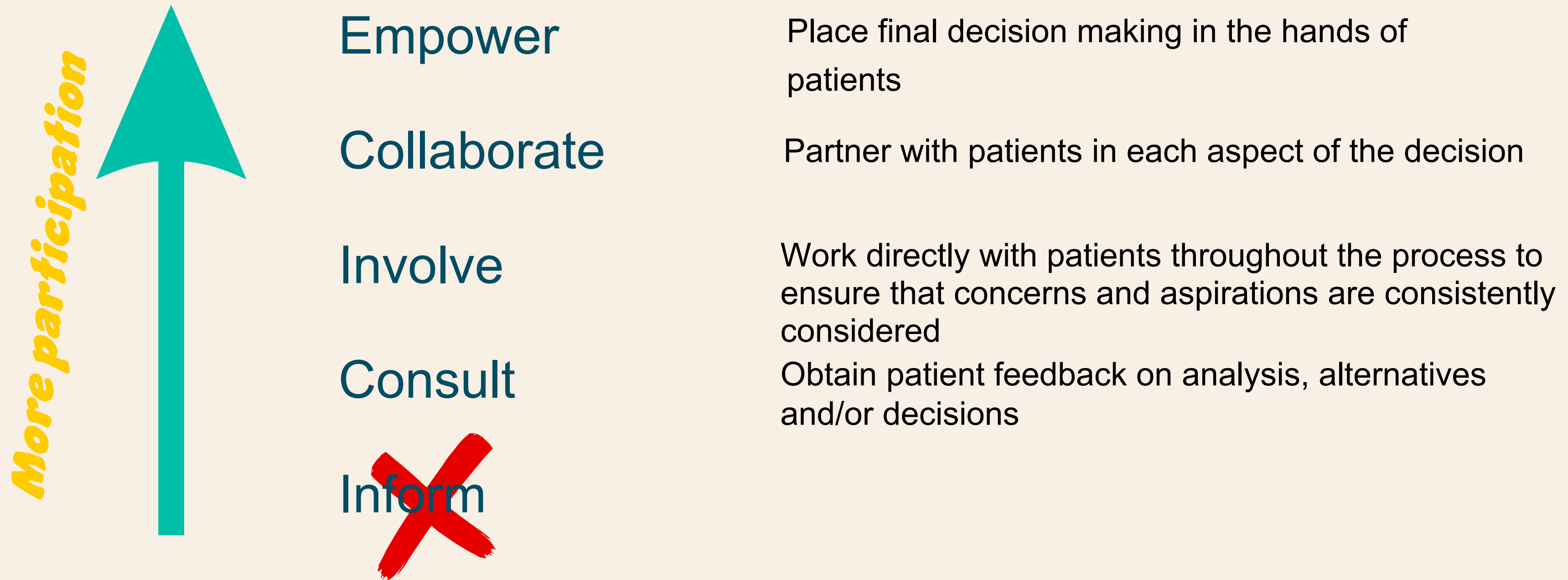


Why is patient engagement in research important?

“From an ethical perspective, meaningful patient engagement:

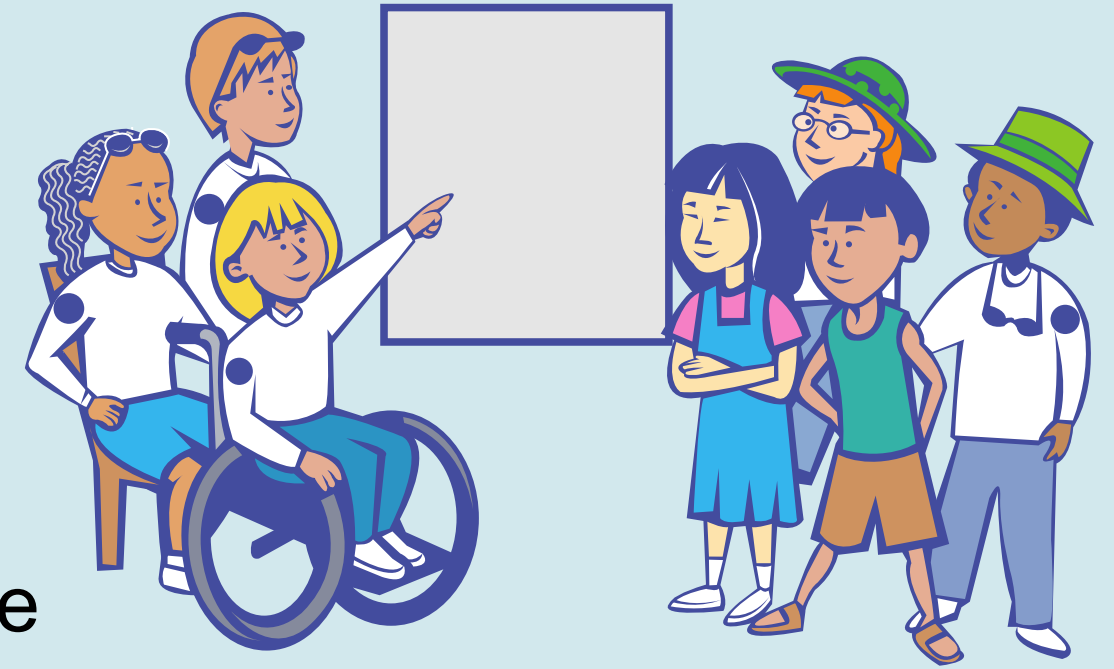
- **grounds research** in a deep understanding of the health situations and the living or lived experiences of actual patients, including groups that are typically underrepresented in research, to make research more relevant and usable by those patients;
- promotes research methods that are **culturally safe, respectful, and appropriate** ;
- **legitimizes research** in the eyes of the community that the research is intended to benefit;
- **strengthens capacity of patients** to shape research that matters to them;
- **builds relationships** among patients and others involved in research that are mutually respectful...”

Levels of engagement



Special considerations for partnering with youth and families

- Youth are often in transitional periods in their lives - impact on time commitment
- Respect youth autonomy (especially with regards to decision making)
- Power imbalances are more pronounced for youth partners
- Caregivers are not restricted to parents (e.g., grandparents, siblings, foster parents, friends)
- Caregiving is not static - demands change rapidly





Patient engagement at every stage



1

Conceptualization

Collaborate to identify priority areas, shape relevant research questions, and highlight real-world needs.



2

Proposal development

Co-develop objectives, outcomes, and approaches that are meaningful to patients and families.



3

Grant writing

Involve patients and families at every stage of grant writing to ensure clarity, inclusivity, and alignment with their priorities.



4

Grant submission

Support your patient partners in fulfilling grant requirements and ensure that everyone has reviewed and approved the final grant submission.





Idea conception

Engaging with patients & families:

- Is this a priority for patients?
- Is there an unmet need?
- Are there research gaps that you could address?
- Does your research have the potential to improve patients' lives?



Group brainstorming



What are some of the
potential questions or challenges
to patient engagement that you think could
come up during stage 1:
conceptualization of your idea



Stage 2: Developing your research proposal



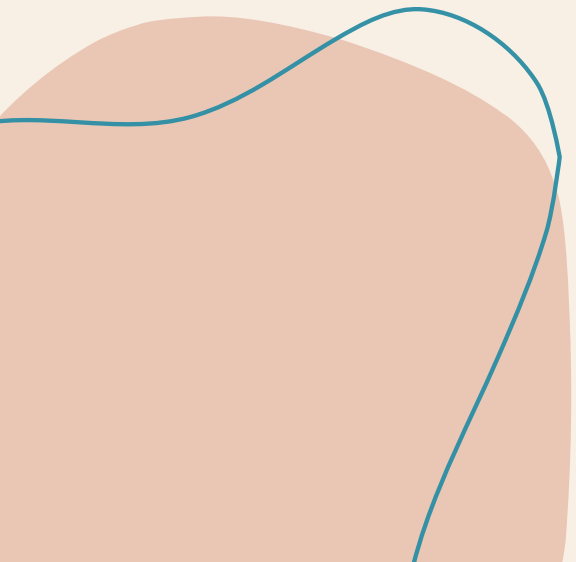
- Refining the research question
- Deciding on methods and outcomes
- Bringing together collaborators

Considerations for engaging with patients & families

- Is my/our research question impactful to patients and families?
- Have we selected outcomes that are important and relevant?
- Do our methods and measurement instruments create any barriers for potential participants ?
- What should patient engagement look like in answering these questions ?



A real-life example

- Research proposal for an extension of a project about family -centred care for children with rare diseases
 - Steering Committee - patient/family partners (5), clinician (1), researchers (3)
 - Additional patient partners (3)
- 

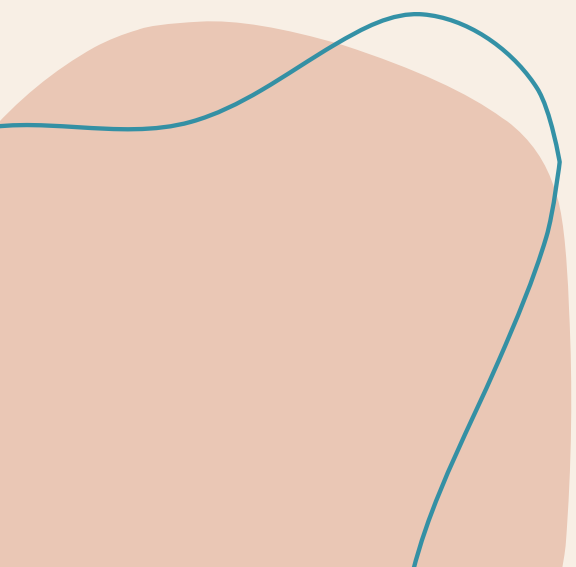
Steering Committee

- Co-leaders on all major decisions
- Group decision on leadership and contribution approach
- Working Together Agreement

“Members of the Co-Designing Inclusive Pediatric Rare Disease Research project came together to create a Working Together Agreement...to build trust and transparency in their engagement”

Additional patient partners

- Contributors to important decisions
- Clear communications of expectations (all sides), confidentiality



Group brainstorming



What are some of the
potential questions or challenges
to patient engagement that you think could
come up during stage 2:
development of the research proposal?



Stage 3: Writing your grant proposal



- Turning your ideas into a written draft
- Seeking feedback from research team members

Considerations for engaging with patients & families

- Have you communicated your patient engagement strategy and how it is embedded in your research?
- Are the roles of your patient partners clearly explained and feasible?
- Have you budgeted for patient engagement?
- Is your proposal written in language that is understandable to reviewers?



What researchers should think about

- Budget enough time for feedback
- Continue building communication
- Your actions are key to building trust

Affirm

Check in



Don't assume

Additional barriers for groups under-represented in research

- May require additional outreach to recruit, and time for relationship building
- Researcher familiarity with issues of EDI and social justice
- Being the 'token minority'
- Partners from low -income families may require additional time, financial support

Group brainstorming



What are some of the
potential questions or challenges
to patient engagement that you think could
come up during stage 3:
writing the grant proposal?

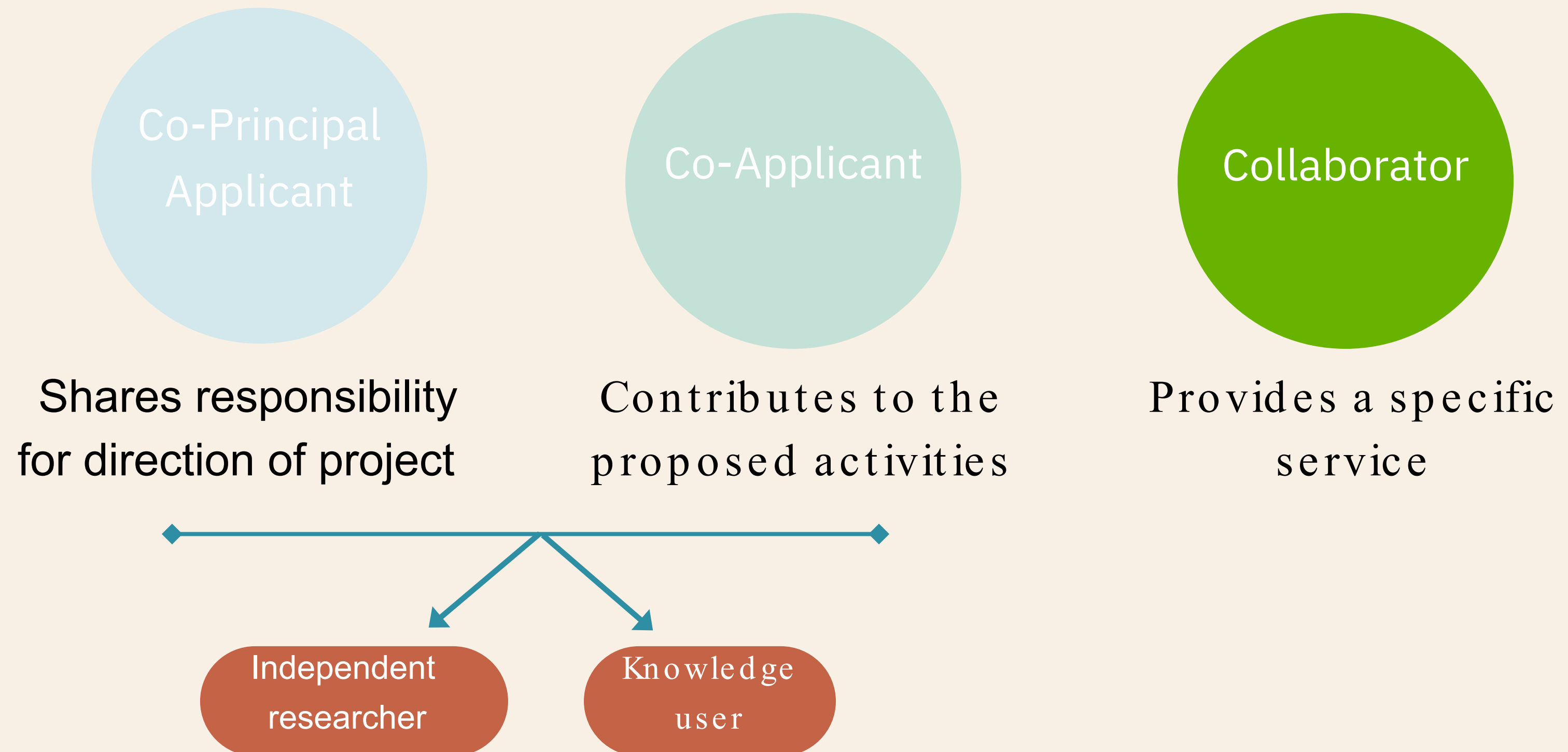


Stage 4: Submitting the grant proposal



- Identify the CIHR role that patient partners will play in your application
- Familiarize yourself with CIHR grant requirements for patient partners
- Support patient partners to fulfill their CIHR grant requirements

CIHR levels of engagement



Application requirements for patient partners

- 1 ResearchNet account, PIN
- 2 Equity & diversity questionnaire
- 3 Applicant Profile CV or Canadian Common CV (CCV)
- 4 Most significant contributions



Guide for Patient Partner Co-Applicants



Guide for Patient Partner Co-Applicants



Thank you for accepting to be a patient partner co-applicant in this Canadian Institutes of Health Research (CIHR) Research Proposal: “_____”.

At CIHR, patient partners are referred to as Knowledge Users. As a Knowledge User on this application, you will be in a co-principal investigator role (defined as an individual who contributes to the proposed activities) if the grant application is successful.

CIHR definition of a Knowledge User

An individual:

- who is likely to be able to use the knowledge generated through research in order to make informed decisions about health policies, programs and/or practices;
- whose level of engagement in the research process may vary in intensity and complexity depending on the nature of the research and their information needs;
- who can be, but is not limited to, a practitioner, policy maker, educator, decision maker, health care administrator, community leader, or an individual in a health charity, patient group, private sector organization or a media outlet;
- additional resources and examples are available on [Knowledge User Engagement](https://cihr-irsc.gc.ca/e/34190.html#k4).

<https://cihr-irsc.gc.ca/e/34190.html#k4>

Phases of this Grant Application

1) Registration

Submitted: _____

- A one-page summary of the proposed research
- Purpose: to ensure that the proposal meets all the criteria for the full application.



2) Full Grant Application

Due: _____

- 10-page grant proposal that will describe the rationale and objectives, research approach, timelines and key deliverables, anticipated impact, and research team
- You will have an opportunity to provide feedback on this application



3) CIHR Decision

Due: _____

- Think positive!



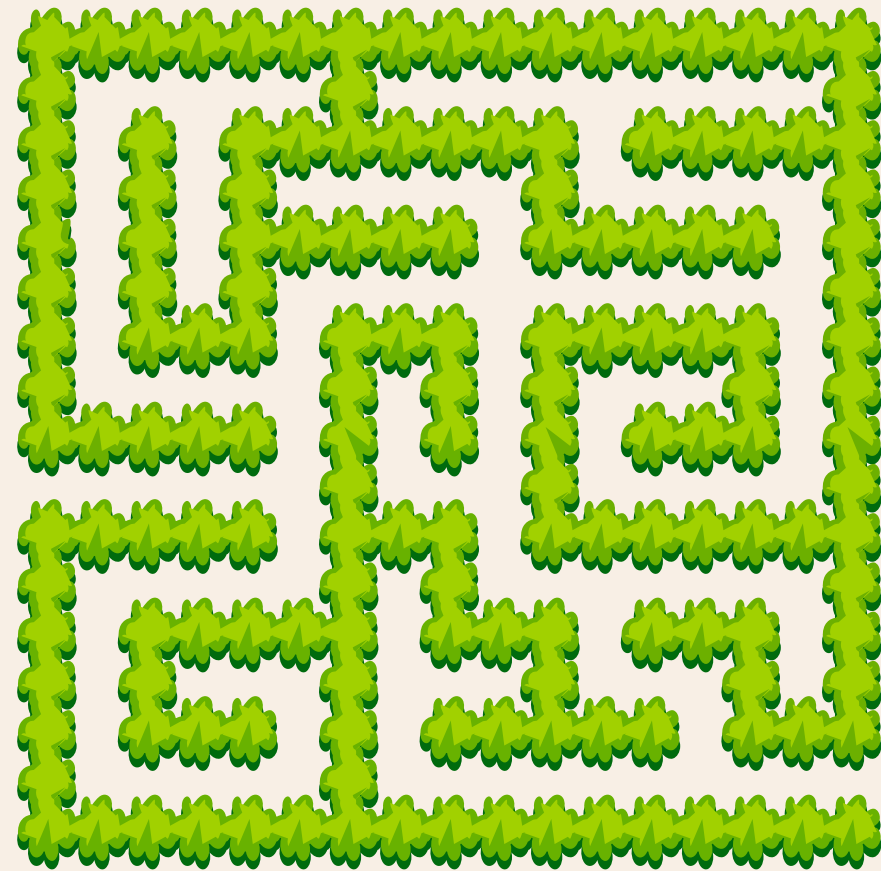
◦ Definition of a Knowledge User

◦ Phases of the grant application & deadlines

◦ “How to”

★ ◦ Generic, adaptable to specific grant applications

Barriers & challenges



- 1 Technology / platform
- 2 Application content
- 3 Language

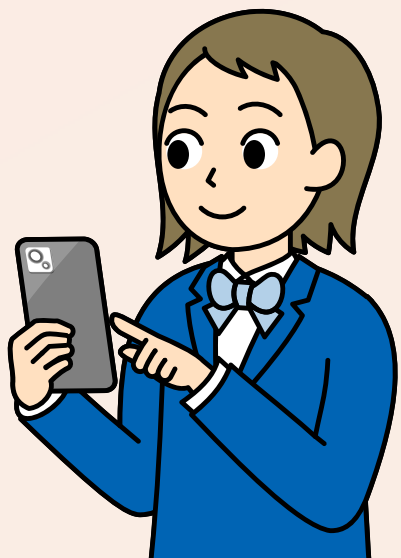
1 Technology / platform

Multiple steps



- Set up ResearchNet account, get a PIN
- Complete the EDI questionnaire
- Full application: CV, Most Significant Contributions, review personal information, consent

Optimized for desktops



- Designed by (and assumes completion by) computer users
- Many patient partners use phones/tablets
- Cannot assume access to Microsoft software

2 Application content

Applicant Profile CV

- Personal statement
- Positions and Honours
- Contributions to Knowledge Creation, Knowledge Sharing, and/or Knowledge Translation
- Other relevant information (optional)

Most Significant Contributions

- Akin to a cover letter

Instructions from CIHR

Personal statement

“Briefly describe how & why you are able to contribute to this project. Relevant factors may include aspects of your training; your previous and/or current work and experience in this area or related areas; **your expertise or living experience** ; and/or performance in this or related fields...”

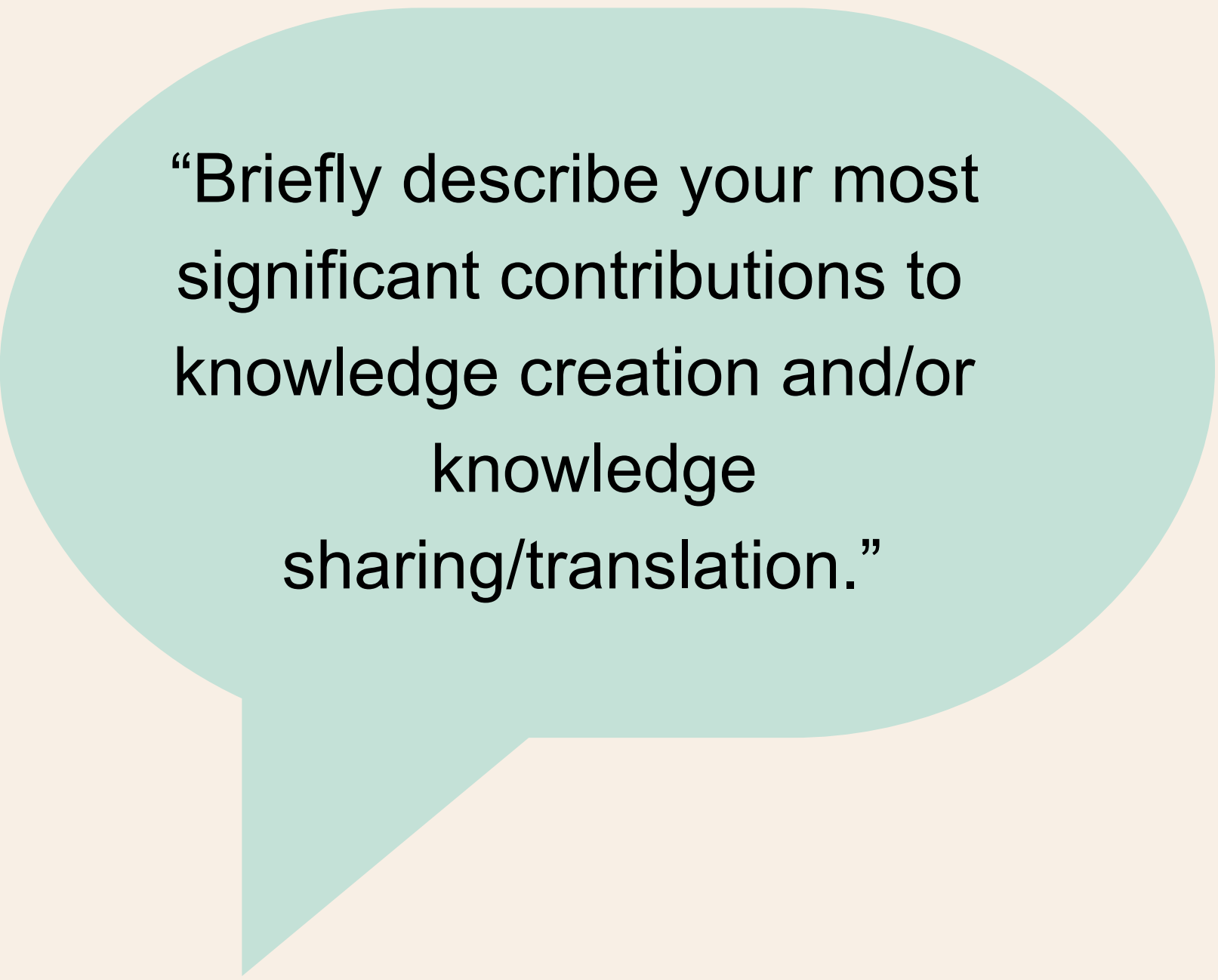
Positions & Honours

“List the positions/roles you have held (or currently hold) that are relevant to this application...”

List any relevant achievements/honours. These may be personal, community-based, academic, or professional.”

Instructions from CIHR cont'd

**Contributions to
Knowledge Creation,
Knowledge Sharing,
and/or Knowledge
Translation**



“Briefly describe your most significant contributions to knowledge creation and/or knowledge sharing/translation.”

Repetition in requirements

Applicant Profile CV

A. Personal Statement

Briefly describe how and why you are able to contribute to this project. Relevant factors may include aspects of your training; your previous and/or current work and experience in this area or related areas; your expertise or living experience; and/or performance in this or related fields. Training may be formal or informal (e.g. mentorship), and you may indicate if you have served as a mentor to others.

B. Positions and Honours

List the positions/roles you have held (or currently hold) that are relevant to this application. These positions do not need to be limited to salaried employment.

List any relevant achievements/honors. These may be personal, community-based, academic, or professional.

C. Contributions to Knowledge Creation, Knowledge Sharing, and/or Knowledge Translation

Briefly describe your most significant contributions to knowledge creation and/or knowledge sharing/translation. (Maximum of 5)

Most Significant Contributions

Please provide information regarding your most significant contributions (maximum of 5) as they relate to the application. Contributions can take the form of:

- Publications, presentations, intellectual property, standards, code, datasets, other knowledge translation activities, etc.;
- Training and mentorship;
- Degrees, credentials, awards, certificates etc.;
- Clinical practice, policy development, community engagement etc.;
- Specialized training, strategic employment positions, etc.

The contributions that you choose to share **should be directly relevant to the grant application** and should demonstrate how you will contribute to the application at hand.

- “Describe how... you are able to contribute to this project”
- Achievement / honours
- Training / mentorship
- “Contribution to knowledge translation activities”

Tips for supporting patient partners to complete application requirements

- Provide guidance
- Assign a contact person from your team
- Actively assist with writing / uploading documents



3 Language

Instructions - Most Significant Contributions



“Please provide information regarding your most significant contributions (maximum of 5) as they relate to the application. Contributions can take the form of:

- Publications, presentations, intellectual property, standards, code, datasets, other knowledge translation activities, etc.;
- Training and mentorship;
- Degrees, credentials, awards, certificates etc.;
- Clinical practice, policy development, community engagement etc.;
- Specialized training, strategic employment positions, etc.

”

15.9

Fleisch -Kincaid Grade
Level

8

Recommended grade
level for consent forms



Tri-agency CV

1. Personal statement

2. Most significant contributions and experiences

3. Supervisory and mentorship activities

- must not exceed five pages (six pages for French)
- write as much as you need for each section (1 through 3), as long as you do not go over the total page limit.

1. Personal statement

Describe why you are well suited for your proposed role relevant to the application.
For example, you may include:

- Collaborations or past performance in the field or related fields.
- Expertise related to the specific topic or related topics.
- Impact of your research, and its benefits to society and science.
- Leadership activities and skills.
- **Lived or living experience.**
- Previous work, progress, or productivity that provide context to the results of your research activities which support your current application.
- Recognitions (e.g., prizes, awards, community letters).

2. Most significant contributions and experiences

Describe up to ten important contributions or experiences that relate to your application. Contributions described in the previous section can be used here.

- Explain the impact, significance, usefulness, and your role in each contribution or experience. A contribution does not have to be a single publication or report. This can include a collection of related publications.
For example, you may include:
Articles and other publications (e.g., communications, monographs, memoirs or special papers, review articles, conference proceedings, government publications, reports documenting industrial contributions or contributions to professional practice, posters, abstracts, preprints).
- Assessment and review activities (e.g., journal review, conference review, funding assessment).
- **Community service or involvement that leverages expertise (e.g., membership on expert/advisory committees, journal editorship, sharing circles, community gatherings, engagement events).**
- Contributions to Indigenous leadership, self-determination, and capacity building in research.
- Creative outputs (e.g., art, exhibitions, performances, publications, presentations, and film, video, and audio recordings).
- Dataset creation, curation, sharing, or re-use.
- Equity, diversity, inclusion, and accessibility advances in the research ecosystem.
- **Event and volunteer activities.**
- Intellectual property (e.g., patents, copyrights, trademarks, trade secrets).
- Knowledge mobilization, including knowledge translation and communication of research results to specialist or non-specialist audiences, including policymakers and the public (e.g., magazine/newspaper articles, media interviews, blogs, social media, policy briefs, public lectures).
- Methodologies, knowledge systems, cultural practices and approaches (e.g., Indigenous knowledge and science).
- New companies or organizations created to further the promotion/use of research.
- **Partnerships or collaborations within or with Canadian or international research or non-profit / public / private sector organizations (e.g., through research networks, large collaborative projects, community information, voluntary work).**
-research communities or non-profit / public / private sector
-engaged research/citizen science, non-academic career
- Policies, guidelines, regulations, laws, rights, standards or practices.
- Products, technology, processes, services, or advice useful to specific organizations (from the private, public, or non-profit sectors), communities, or society.
- Software or tool development for use by researchers or others in the private or public domain.

3. Supervisory and mentorship activities

Describe how you have helped mentor or train future generations. This can include the development of highly qualified personnel for careers within and outside of academia.

For example, you may include:

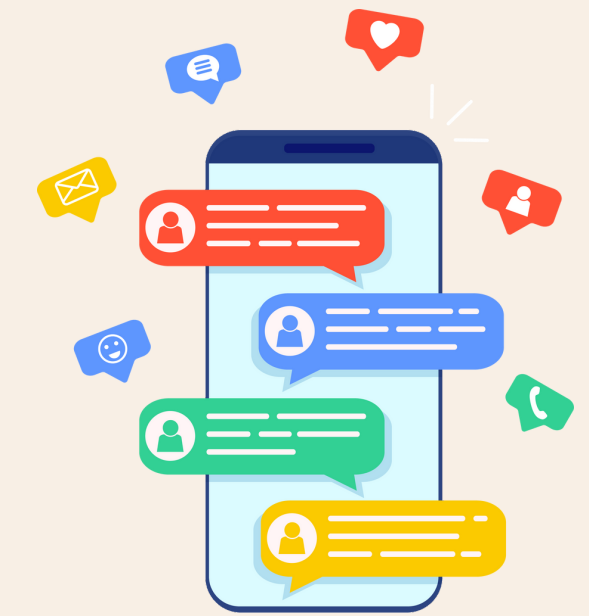
- Creation of safe, equitable, and inclusive research environments, practices, and norms.
- Development and delivery of training workshops outside of research or course requirements.
- Mentorship (formal or informal) of highly qualified personnel, Early Career Researchers, colleagues, collaborators, relevant partners, other professionals, or community members.
- Outreach and engagement with students, youth, or members of the general public , including through in -person or online targeted activities or capacity building.
- Supervision of highly qualified personnel in the research process.
- Training in methodologies, knowledge systems, or cultural practices and approaches in the research context (e.g., Indigenous knowledge and science).

Group brainstorming



What do you see as potential challenges and
barriers for patient partners with this Tri-
Agency Narrative CV?

Key messages



1. Learn the basics of patient engagement (webinars, self-paced learning modules, etc.) People are bringing their lives into this!
2. Patient engagement is important at every stage.
3. Don't be afraid of being challenged - answer honestly and explain your opinion.
4. Be prepared to support your patient partners to fulfill CIHR grant requirements.
5. Communicate the results! They are invested in this work too.



Collaborators

Dr. Beth Potter

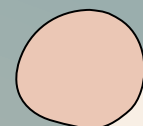
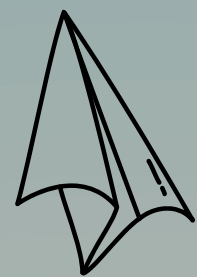
Priscilla Medeiros

Nicole Pallone

Biba Tinga

Bilqis Williams

Andrea Yu



**Thank
You**



Andrea Chow
achow@uottawa.ca

Maureen Smith
maureen_smith@rogers.com
[@maureenchat.bsky.org](https://bsky.app/maureenchat)



**INFORM
RARE**