Canadian Institutes of Health Research survey for persons with disability or health conditions

Thank you for participating in our survey. The information you share will help us co-develop an action plan on accessibility and systemic ableism.

The questions in this survey ask about your **personal experiences** with **ableism and barriers to accessibility** in the health research funding system. This may be triggering for some people and may cause harm. You may quit the survey at any time. If you need support during or after completing the survey, please go to "**what can I do if I am feeling distress**?" in the <u>Frequently Asked Questions</u> section on our website for links to resources.

Instructions

Most of the questions have response options in a list. For these questions, place an "X" in front of the option or options that you want to choose.

Some questions have a space to put your own answers. An asterisk (*) marks the beginning of where you can put your answer.

You may not need to answer all the questions. There are instructions before each question indicating whether that question is relevant to your experiences. For example, if you have never applied to CIHR for funding, you will not need to answer the questions about the application process.

Please <u>send your answers</u> by email to <u>edi@cihr-irsc.gc.ca</u>. Your answers may be in written form or in an audio or video recording. If you prefer to give us your answers by phone or in a virtual meeting, please contact us. Our <u>contact information</u> can be found on the last page.

Tell us about how you have interacted with the health research funding system

There are barriers that make it harder for people with disabilities, or with health conditions that affect how they interact with the health research funding system, to fully take part in health research. This section will ask you questions about how you have interacted with the health research funding system.

In this survey, when we say "the health research funding system" we mean funding organizations such as the Canadian Institutes of Health Research (CIHR) and academic or research institutions (for example, universities or research institutes).

- 1. How have you interacted with CIHR? (You may pick more than one answer)
 - I have applied for funding from CIHR
 - I am eligible to apply for funding from CIHR, but have not done so because of ableism or barriers related to accessibility
 - I have received funding from CIHR
 - I supervise, or I have supervised, a student or trainee who has applied for or received CIHR funding
 - I have applied to be a peer reviewer for CIHR
 - o I am, or I have been, a peer reviewer for CIHR
 - o I have applied to be a member of a CIHR advisory group
 - I am, or I have been, a member of a CIHR advisory group
 - I have never interacted with CIHR
 - Other. Please tell us more here: *

- 2. How have you interacted with other research funding agencies? (You may pick more than one answer)
 - o I have applied for funding from another research funding agency
 - I am eligible to apply for funding from another research funding agency, but have not done so because of ableism or barriers related to accessibility
 - o I have received funding from another research funding agency
 - I supervise, or I have supervised, a student or trainee who has applied for or received funding from another research funding agency
 - I have applied to be a peer reviewer for another research funding agency
 - I am, or I have been, a peer reviewer for another research funding agency
 - I have applied to be a member of an advisory group for another research funding agency
 - I am, or I have been, a member of an advisory group another research funding agency
 - I have never interacted with another research funding agency
 - Other. Please tell us more here: *
- 3. Which area best describes your involvement in health research? (You may pick more than one answer)
 - o Biomedical (for example, neuroscience, cancer biology, etc.)
 - Clinical (for example, rehabilitation, psychotherapy, dermatology, etc.)
 - Critical health research (for example, critical disability studies, deaf studies, neurodiversity studies, etc.)
 - Health systems and services (for example, health policy, medical economics, etc.)
 - Population health (for example, public health, medical anthropology, etc.)
 - Other. Please tell us more here: *
 - None. I am not involved in health research.

Questions about ableism or barriers to accessibility at CIHR

This section will ask you questions about the types of barriers or issues of ableism you have **personally experienced when interacting with CIHR**.

Applying to CIHR for funding

Instructions: Answer questions 4 and 5 if you have applied for funding and are eligible to apply but have not done so because of barriers or have received funding from CIHR. If not, please skip question 4 and 5, and go to question 6.

- 4. When **applying to CIHR** for a grant or award, I have had difficulty... (You may pick more than one answer)
 - Finding information about accessibility and accommodations
 - Finding information about how to apply or about a program (e.g., eligibility requirements)
 - Accessing webpages or specific information on webpages
 - Communicating with CIHR staff
 - Meeting eligibility requirements of grant and award programs
 - Completing training modules (for example, Sex and Gender in Biomedical Research learning module)
 - Participating in informational activities (for example, Project Grant funding opportunity webinars)
 - Using ResearchNet (CIHR's application system)
 - o Using the Canadian Common CV system
 - Filling out, or submitting, application templates or other forms in the required format
 - o Receiving accommodations to submit an application
 - Needing to provide proof of disability, sometimes repeatedly
 - Finding space in application templates or forms to include disability-related fields, methods, or costs
 - Finding space in application templates or forms to include nontraditional forms of knowledge, community engagement, and/or research
 - Finding information about when and how to include concepts of disability and accommodation in my research proposal

- Other barriers in the application process. Please tell us more here:
- a. If there is more you would like to tell us about the barriers or ableism you have experienced when applying to CIHR, please tell us here: *
- b. If you have ideas for how we can make our application process more accessible and inclusive, please tell us here: *

Peer Review at CIHR

Instructions: If you have applied for funding or have received funding from CIHR, please answer question 5. If not, please skip this question and go to question 6.

- 5. When my application(s) went through the **peer review process at CIHR**, I experienced a lack of understanding or bias related to... (You may pick more than one answer)
 - Accommodation needs and/or budget for myself, research team members (including patient or community partners), students or trainees to fully participate in the research project
 - Accommodation needs and/or budget for accessible research design
 - o Including participants with disabilities as participants in research
 - Eligibility requirements for grant or awards
 - How having a disability impacts career progression
 - How having a disability impacts traditional measures of research productivity
 - How having a disability impacts traditional measures of research excellence
 - Disclosing a disability
 - Disability-affirming theories or methods
 - Not having enough time to apply to a grant or award or to respond to peer review comments
 - Other areas of assessment within the peer review process. Please tell us more here: *
 - a. If there is more you would like to tell us about experiences with barriers to accessibility or issues of ableism as your application(s) went through peer review at CIHR, please tell us here: *

b.	If you have ideas for how we can make our peer review process more accessible and inclusive, please tell us here: *

Instructions: If you have applied to be a peer reviewer or have been a peer reviewer for CIHR, please answer question 6. If not, please skip this question and go to question 7.

- 6. As a peer reviewer (or potential peer reviewer) for CIHR, I have had difficulty... (You may pick more than one answer)
 - Finding information about accessibility and accommodations
 - Accessing webpages or specific information on webpages
 - o Communicating with CIHR staff or Committee Chair
 - Meeting eligibility requirements for the role of reviewer-in-training, peer reviewer or College of Reviewers membership
 - Completing training modules (for example, Conducting Quality Reviews learning module)
 - Participating in informational activities (for example, reviewer webinars)
 - Using ResearchNet
 - Using Canadian Common CV
 - o Filling out review templates or other forms
 - o Receiving accommodations to review an application
 - Receiving accommodations to participate in peer review meetings
 - Evaluating, or finding information about, when and how concepts of disability and accommodation are included in research proposals
 - Accessing other parts of the peer review process. Please tell us more here: *
 - a. If there is more you would like to tell us about the barriers to accessibility or issues of ableism you have experienced as a peer reviewer (or a potential peer reviewer) at CIHR, please tell us here: *
 - b. If you have ideas for how we can make our peer review process more accessible and inclusive, please tell us here: *

Funding policy at CIHR

Instructions: If you have received funding from CIHR, please answer question 7. If not, please skip this question and go to question 8.

- 7. When applying the **rules for using CIHR funds**, I have had difficulty... (You may pick more than one answer)
 - Finding information about using CIHR funds for accommodations for myself, a research team member (including patient or community partners), or a student or trainee
 - Coordinating responsibility for accommodations between CIHR and my organization
 - Getting funding for accommodations to conduct research
 - Getting funds for accommodations for research-related activities (for example, accommodations for travel)
 - Getting funding for accommodations to network, attend learning events, or share my research findings (for example, conferences)
 - Getting funding for accommodations that is separate from my research budget
 - Getting funding for paid leave for myself, a research team member, or a student or trainee
 - Meeting eligibility requirements of grant and award programs (for example working part-time)
 - Other areas of funding policy. Please tell us more here: *
 - a. If there is more you would like to tell us about barriers to accessibility or issues of ableism related to rules for using CIHR funds, please tell us here: *
 - b. If you have ideas for how we can make our rules for using CIHR funds more accessible and inclusive, please tell us here: *

Providing advice and guidance to CIHR

Instructions: If you have applied to be a member of a CIHR advisory group or have been a member of a CIHR advisory group, please answer question 8. If not, please skip this question and go to question 9.

- 8. As a patient partner, community partner or member (or potential partner or member) of an advisory group for CIHR, I have had difficulty.... (You may pick more than one answer)
 - Finding information about accessibility and accommodations
 - Accessing webpages or specific information on webpages
 - Applying for membership in an accessible format
 - Communicating with CIHR staff
 - Meeting eligibility requirements for advisory groups
 - Getting accessible meeting materials or other documents I need to participate
 - o Filling out review templates or other forms
 - o Getting the accommodations needed to participate in meetings
 - Accessing other activities related to participating on an advisory group. Please tell us more here: *
 - a. If there is more you would like to tell us about the barriers to accessibility or issues of ableism you have experienced as a patient partner, community partner, or member of an advisory group, please tell us here: *
 - b. If you have ideas for how we can make providing advice and guidance to CIHR more accessible and inclusive, please tell us here:

Questions about ableism or barriers to accessibility in other areas of the health research funding system

We know that ableism and barriers to accessibility exist in other areas of the health research system. CIHR would like to work with others to make things better. This section will ask you questions about the types of barriers you have experienced **outside of CIHR**.

Other funding organizations

Instructions: If you have interacted with other research funding agencies in any way, please answer question 9. If you have never interacted with another research funding agency, please skip this question, and go to question 10.

- 9. Let us know if you have experienced ableism or barriers to accessibility when **interacting with other research funding organizations**. I have experienced... (You may pick more than one answer)
 - Barriers finding information related to accessibility
 - o Barriers communicating with funding organization staff
 - o Barriers to accessibility when applying to a grant or award program
 - o Barriers to participating in peer review or in assessing applications
 - Lack of understanding or bias in the review of my application
 - Lack of understanding or bias when disclosing a disability or making an accommodation request
 - Challenges using funds for accommodations to complete my research
 - Other barriers or issues of ableism. Please tell us more here: *
 - a. We want to learn about what is working well at other research funding organizations. If you have had a positive experience with a research funding organization that has accessible and inclusive policies, practices, or procedures, please tell us about their good work here: *

Academic or research institutions

Instructions: If you have experienced ableism or barriers to accessibility at academic or research institutions, please answer question 10. If not, please skip this question and go to question 11.

- 10. Let us know if you have experienced ableism or barriers to accessibility when interacting with academic or research institutions (for example universities, colleges, hospitals, etc.). I have experienced... (You may pick more than one answer)
 - Discrimination based on having a disability or having disclosed a disability
 - Expectations to fit within work standards of abled people
 - Inaccessible work environment
 - Little or no support for accommodations
 - o Unclear policy on accommodations
 - Lack of transparency on the process of seeking accommodations
 - Inaccessible documents or webpages
 - Burden of having to prove a disability
 - Narrow definition of disability
 - o No access to disability-related leave
 - Limited flexibility for part-time work
 - Limited, or no, compensation for my work as compared to others at my career stage
 - Other barriers or issues of ableism. Please tell us more here: *
 - a. CIHR is committed to working with academic and research institutions to help find, fix and prevent barriers and ableism. If you have ideas for how we can work together, please tell us here: *

Other experiences of ableism or barriers to accessibility in the health research funding system

11. If there anything else you would like to tell us about accessibility and ableism in the health research funding system, please tell us here: *

Participant Background

Please tell us a bit about yourself so that we will be able to describe the groups of people who answered our survey.

- 12. I am a.... (You may pick more than one answer)
 - Researcher
 - Postdoctoral researcher
 - Graduate student
 - Undergraduate student
 - Professor or teacher of post-secondary students (e.g., undergraduate, graduate)
 - Supervisor or mentor of post-secondary students, trainees, or early career researchers
 - o Research staff (e.g., lab technician)
 - Clinician
 - Knowledge user or holder
 - Patient partner or community partner
 - Non-academic staff (e.g., administrator)
 - Other or none of the above. Please tell us more about your link to the health research system here:
 - I used to be one of the above. Please tell us more here about why you left the health research system here: *
- 13. The organization I work for, volunteer for, or am most closely associated with is a... (You may pick more than one answer)
 - Government department or agency
 - o Healthcare organization
 - o Indigenous organization
 - Not-for-profit (for example, a charity, foundation, or community-based organization)
 - o For-profit or private organizations
 - Post-secondary institution (for example a university, college or, cégep)
 - o I am not associated with any organization
 - Other. Please tell us more here:

- 14. Where do you live?
 - Alberta
 - British Columbia
 - Manitoba
 - New Brunswick
 - Newfoundland and Labrador
 - Northwest Territories
 - Nova Scotia
 - Nunavut
 - Ontario
 - o Prince Edward Island
 - Quebec
 - Saskatchewan
 - Yukon
 - Outside Canada. Please tell us where you live: *
- 15. The <u>Accessible Canada Act</u> defines a disability as "any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment or a functional limitation whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person's full and equal participation in society."

Do you identify as a person with a disability?

- o Yes
- o No
- o I prefer not to answer

Instructions: If you answered "yes" to question 15, please tell us a bit more about your disability by answering questions 15a, 15b and 15c. If you answered "no" or "I prefer not to answer", please go to question 15d.

- a. Do you identify as having...?
- A visible disability or disabilities
- An invisible disability or disabilities
- Both visible and invisible disabilities
- I prefer not to answer
- b. I was...
- Born with my disability or disabilities
- My disability or disabilities happened after birth
- I was born with a disability or disabilities, and I have another disability or disabilities that happened after birth
- o I prefer not to answer
- c. Please tell us more about the type of your disability (You may pick more than one answer)
- Hearing
- Seeing
- Mobility
- o Flexibility
- Dexterity
- o Pain-related
- Learning
- o Mental health-related
- Memory
- Neurodiverse
- o Disability related to how I communicate
- Disability not listed. Please tell us more here: *
- o I prefer not to answer

d.	You told us you do not identify as having a disability. Do you identify
	as having a chronic health condition that affects how you interact with
	the health research funding system?

- o Yes
- o No
- o I prefer not to answer
- 16. Please pick the gender identity that best describes how you currently think of yourself.
 - o Gender-fluid
 - Man
 - Non-binary
 - Trans man
 - Trans woman
 - Two-spirit
 - Woman
 - o I don't identify with any option listed. I identify as: *
 - o I prefer not to answer
- 17. Please pick the sexual orientation that best describes how you currently think of yourself.
 - Asexual
 - Bisexual
 - o Gay
 - o Heterosexual
 - Lesbian
 - Pansexual
 - Queer
 - o Two-Spirit
 - o I don't identify with any option listed. I identify as: *
 - I prefer not to answer

18. M	Do you identify as Indigenous? Meaning that you are First Nation, étis, or Inuk (Inuit).
0	Yes
0	No
0	I prefer not to answer
a.	If yes, please tell us which group(s) you identify with. (You may pick more than one answer)
0	First Nation
0	Inuit
0	Métis
0	I prefer not to answer
19.	Do you identify as a person of colour?
0	Yes
0	No
0	I prefer not to answer
20. m	Please tell us which population group you identify with. (You may pick ore than one answer)
0	Arab
0	Black
0	Chinese
0	Filipino
0	Japanese
0	Korean
0	Latin American
0	South Asian (for example, East Indian, Pakistani, Sri Lankan, etc.)
0	Southeast Asian (including Vietnamese, Cambodian, Laotian, Thai,
	oto)

o West Asian (for example, Iranian, Afghan, etc.)

o I prefer not to answer

o I do not identify with any population group listed above. I identify as: *

- 21. What language did you first learn in childhood and still understand? (You may pick more than one answer)
 - o English
 - o French
 - American sign language (ASL)
 - o Indigenous sign language
 - o Langue des Signes Québécoise (LSQ)
 - o Another language
 - o I prefer not to answer
- 22. What language do you use most often at home? (You may pick more than one answer)
 - o English
 - French
 - American sign language (ASL)
 - o Indigenous sign language
 - o Langue des Signes Québécoise (LSQ)
 - o Another language
 - o I prefer not to answer
- 23. I use assistive reading technologies and/or augmentative and alternative communication devices.
 - Yes
 - o No
 - o I prefer not to answer

How to send us your answers

Please send your answers by email to edi@cihr-irsc.gc.ca. Your answers may be in written form or in an audio or video recording. If you prefer to give us your answers by phone or in a virtual meeting, please contact us.

Contact Information

Email: edi@cihr-irsc.gc.ca

Telephone: 1-888-603-4178

- If you speak **English**, press the number **1** when you call the phone number.
- If you speak French, press the number 2 when you call the phone number.
- After you press 1 or 2, press the number 4 to speak to a CIHR staff member.

Thank you!

We sincerely appreciate your time, energy, and thoughtful answers. A summary of the information from this survey will be posted on our Accessibility and Systemic Ableism webpage.

If you need support after completing this survey, please go to the "what can I do if I am feeling distress?" in the <u>Frequently Asked Questions</u> section for links to resources.