

---

# BECOMING A PATIENT PARTNER IN RESEARCH

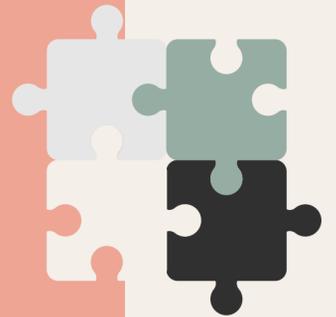
A guide for youth and young adults!

## 1. WHAT IS RESEARCH?

- The process of discovering new facts and gaining knowledge
- Health research helps people learn about:
  - The risk factors and symptoms of different conditions
  - How well treatments work
  - Different experiences with health services

## 2. WHY IS RESEARCH IMPORTANT?

- Allows gaps in knowledge to be filled
- Helps develop new treatment options
- Allows for improvement of patient outcomes
- Gives people a chance to share their lived experiences



## 3. WHAT IS A PATIENT PARTNER?

- As a patient partner, you may be involved in the following stages of research: decision-making, design, planning, delivery, and evaluation of the research study
  - Patient partners usually have a lot of lived experience as a patient, family member, or care provider
  - Your firsthand knowledge, insight, and experience improves research by ensuring that it is relevant and appropriate
-

---

## 4. WHAT ARE THE BENEFITS OF BEING A PATIENT PARTNER?

- Learn more about the healthcare system and health research
- Use your lived experiences to improve the overall healthcare system
- Learn about careers within healthcare and research
- May receive payment, volunteer hours, or recognition for your involvement



## 5. HOW CAN YOU FIND OPPORTUNITIES TO BECOME A PATIENT PARTNER?

- Ask your healthcare providers (physician, nurse, etc.) about any opportunities
- Find a Patient Advisory Council (or something similar) at your hospital or clinic
- Subscribe to newsletters from research organizations such as [CanChild](#)
- Explore youth engagement networks or advocacy groups for relevant opportunities



## 6. WHAT QUESTIONS SHOULD YOU ASK IF YOU ARE CONSIDERING BECOMING A PATIENT PARTNER?

- What is my role in the study and what does my involvement look like?
- Will I be compensated for my involvement? If so, what will this look like?
- Do I need consent from my parent/guardian to participate?
- How will the research team make sure that the activities are accessible for me?

## 7. HOW CAN FAMILY MEMBERS BE INVOLVED?

- Some youth become patient partners on their own. Others become patient partners with the support of their family or other people they trust. Both are common!
- Sometimes researchers might also want to hear from family members to learn about their experiences, so some studies may specifically request family involvement.
- If you are under 18 years old, your parent/caregiver might need to give you permission to participate. The research team can usually tell you if this is a requirement.



## 8. WHERE CAN YOU LEARN MORE ABOUT ENGAGEMENT IN RESEARCH?

A list of additional resources can be found at the link below!

