



# Youth Patient Partners

## Guide for Youth Patient Partners Engaging in a Research Project

This guide is designed for youth who are joining a research team as patient partners, bringing their experience to help inform and guide the research. Researchers may also call this role “person with lived experience partner” (PWLE or PLEX partner). The guide serves as a companion to [TRANSFORM HF's Getting Oriented Guide](#) and summarizes key questions and tips to support your meaningful involvement in research involving youth.

### Finding the Balance Between School and Research

#### QUESTIONS TO ASK YOURSELF

- Can you fit the work on the research team into your school schedule?
- Has the research team provided you with flexible meeting times?
  - For example: after school hours, summer break, and weekends.
- Are there asynchronous options for your meetings or can you get a recording?
- Is there a schedule/calendar platform to manage meetings with the team?
- Do you feel comfortable asking the research team for less responsibility if it is interfering with your schoolwork?

#### ACTIONS TO TAKE

- You are not expected to sacrifice your education - school is your primary responsibility.
- Be honest with the research team about your time and availability to participate.
- Let the research team know if you need a break during busy school periods or if you're feeling overwhelmed with your workload (e.g. exam season, vacation, or summer camp).
- Ask for meeting schedules ahead of time. This will help you manage and plan your time efficiently.
- Add your research tasks and meetings to your school agenda for a full view of your workload.
- Divide your work into manageable chunks; don't take on too much at once.
- Ask the research team to create a [Terms of Reference](#) to outline your involvement in the project, expected hours, compensation and recognition.

### Involving Your Parent/Caregiver

#### QUESTIONS TO ASK YOURSELF

- Do you need permission or consent from your parent/caregiver to participate in the research project?
- To what extent should parents/caregivers be involved in the research project? How involved do you want your parent/caregiver to be?
- Is the research team looking for my opinion or the opinion of my parent/caregiver?
- Are you able to express your own opinions and make any decisions about your role as a patient partner?

#### ACTIONS TO TAKE

- If it's helpful to you, bring your parent/caregiver to the first (or all) team meeting(s) for extra support.
- Set boundaries with your parent/caregiver around your independence. They can act as a support system, but you decide what to share/say/do.
- Share your meeting schedule and project tasks with your parent/caregiver if you need help managing your work and time.
- If you are struggling to advocate for yourself, ask your parent/caregiver step in to raise any concerns or feelings.
- If something is unclear, have your parent/caregiver review any documents and emails with you or help you in filling them out.

## Coordinating with Your Appointments

### QUESTIONS TO ASK YOURSELF

- What clinical appointments do you have that might conflict with the research project (both in-person and virtual)?
- Have you considered how you feel after the appointments (e.g., are they chill or will you need time to recover and feel better)?
- How can the research project fit in around your appointments?

### ACTIONS TO TAKE

- Schedule around clinical appointments or testing so you aren't too tired or overloaded.
- Consider what is happening in the appointment – will it be easy or demanding on you? How will you feel afterwards?
- Adjust your involvement if you need extra time afterwards to focus on your health and school.

## Fostering Trust with the Research Team

### ACTIONS TO TAKE

- Know who your primary contact is and build a relationship with that person.
- Don't be afraid to ask for help if you don't understand something. Everyone has to learn at some point!
- Your voice matters and will help shape the research - share your experiences and thoughts that you're comfortable with.
- The team is there to support you, let them know if something's wrong or if you are uncomfortable.
- Identify a person on the research team that you feel safe around. Contact them if you have any questions or issues.
- Take the time to learn about the people you're working with. Ask questions about their roles and backgrounds.

## Building Your Resume and Securing References

### QUESTIONS TO ASK YOURSELF

- Are you noting down the skills you are gaining as you work on this project? How would you describe these in your resume?
- How could the researcher/principal investigator (PI) and members of the research team help support your future work/school opportunities?
- Have you asked them to act as a reference or to provide a letter of recommendation?
- Have you added your experience to your resume or curriculum vitae? Included it on your LinkedIn profile?

### ACTIONS TO TAKE

- Working as a patient partner on a research project is real experience. Include your role in your resume as you apply for job and postsecondary applications.
- Write down the contact information for each member of the research team.
- Working on a project as a patient partner could be helpful in scholarship applications for postsecondary opportunities. Make sure to include your patient partner role when applying.
- List your experience in your resume (under the 'work experience' or 'research experience' section):

#### Patient Partner

Title of research project, year

Name of Institution (e.g., SickKids, UHN)

- Developed ...
- Led ...
- Reviewed ...
- Contributed ...

## Being Compensated and Recognized for Your Participation

### QUESTIONS TO ASK YOURSELF

- Is your involvement in the research project eligible for school volunteer hours?
- Can your parent/caregiver support you with your financial paperwork and processes, for example taxes, direct deposit?
- When will you receive payments and what steps do you need to take to get it?
- Learn more: [Patient Recognition and Compensation Policy](#)

### ACTIONS TO TAKE

- Ask your school guidance counselor if your role qualifies for volunteer hours.
- You are to be equally compensated for your contributions to research as adult patient partners.
- Track your hours and contributions for school credit or future opportunities.

### Resources and Support



- [Becoming a patient partner in research: a guide for youth and young adults!](#)
- [We're Engaging Younger Patient Partners! Here's How](#)
- [Tamarack Institute: Meaningfully engaging youth](#)
- [10 Tips for Engaging Young People in Research](#)
- [SickKids: Youth and Family Specific Engagement in Research \(UNITE\): A Framework Development Project](#)
- [Centre for Addiction and Mental Health \(CAMH\): Youth Engagement Initiative](#)
- TRANSFORM HF's [Patient Partner Terms of Reference](#)
- TRANSFORM HF's [Getting Oriented: A Guide for Patient Partners Engaging in a Research Project](#)
- TRANSFORM HF's [Patient Recognition and Compensation Policy](#)

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