

Additional Resources

Grant Applications

Equity, Diversity & Inclusion, & Anti-Racism

Ethics in Engagement

Training for Research Staff



Step 1:
Capacity & Readiness

Step 3:
Onboarding

Step 4:
Collaboration

Step 6:
Establishing Expectations

Step 7:
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ROADMAP FOR YOUTH ENGAGEMENT IN RESEARCH

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Youth engagement in research is the intentional and meaningful involvement of youth across the research process. Engaging youth helps ensure that research questions, processes, and findings are relevant, and impactful. Despite the growing implementation of youth engagement, there remain risks of unintended harms, including tokenistic involvement and power imbalances.



As a result, research teams require practical, hands-on resources to support meaningful youth engagement throughout the research process. In response, we co-created this roadmap with SickKids research staff and youth to support research teams in engaging youth meaningfully.

This roadmap is designed to provide practical strategies and tools to support SickKids research teams in planning, implementing, sustaining, and evaluating youth engagement in research. We gratefully acknowledge funding from the Child Health Evaluative Sciences (CHES) through a Special Projects Grant and thank the SickKids research staff and youth partners whose contributions made this work possible.

This is a living document and will be updated regularly as best practices continue to evolve.



How to use this Roadmap?

- Links on this roadmap are formatted as follows: [Link](#)
- We would encourage you to start at [Step 1: Capacity and Readiness](#), but feel free start at any step that best fits your needs.
- You can choose to supplement your learning by referring to our [Additional Resources](#) 
- You can return to the roadmap by clicking on  [Return to Roadmap](#) located on the bottom left corner of each page.

Disclaimer: This roadmap is intended for use by staff at SickKids. While others may find it helpful, it was developed within the SickKids context and should be adapted as needed for use in other settings.



What is Youth Engagement in Research?

- Intentional and meaningful involvement of youth across the research process, ensuring youth perspectives shape decision-making and contribute to positive change^{1,2,3}
- Recognizing lived experience as a valuable form of expertise^{3,4}



Why Engage Youth in Research?

- Enhances research impact and relevance by rooting it in youth's lived experience and subsequently improve youth health outcomes³
- Rewarding experience for both youth and research teams³



What are the Challenges of Youth Engagement for Youth?³

- Tokenism or superficial involvement
- Power imbalances between youth and research teams
- Read more about challenges to patient engagement here (e.g., unconscious bias, lack of support):
 - [Richards et al., 2023](#)



What are the Levels of Engagement?⁵

- Youth engagement exists on a spectrum, and not all projects require the highest level of involvement. The continuum includes:

Inform

Share or receive information to build awareness

Consult

Seek youth input on specific aspects of research

Involve

Co-develop outcomes with youth throughout the project

Shared Leadership

Partner with youth through joint decision-making and leadership roles

Less Involvement ←

→ More Involvement



What is a Youth Partner?

- A youth research partner is a young person who collaborates with research teams throughout the research process by sharing their perspectives, experiences, and ideas to help shape and improve the study.³



What are the Benefits of Youth Engagement for Youth?³

- Increase self-esteem and empowerment
- Develop a sense of community
- Build capacity for youth to develop research, communication, and advocacy skills



What Frameworks Exist to Engage Youth in Research?

- Engagement frameworks have been developed to address challenges related to youth engagement. Examples include:
 - [SickKids Framework for Engagement](#)
 - [McCain Model for Youth Engagement](#)
 - [7P Model for Youth Engagement](#)



STEP 1: CAPACITY AND READINESS

This step facilitates reflection prior to engagement by helping teams explore key areas that support meaningful and ethical youth engagement, recognize existing strengths, and identify where additional support or planning may be needed. **You are not expected to have all the answers. These questions are meant to guide reflection and inform next steps.**



Team Readiness and Commitment^{6,7}:

- Is the team aligned on the purpose of engaging youth?
- Is there willingness to adapt research processes based on youth input?
- Has the team engaged youth meaningfully in previous projects? What worked and what didn't work?
- How will the team ensure youth perspectives inform decision-making throughout the study, not just in early phases?



Time and Staffing^{6,7}:

- Who on the team is responsible and has capacity for coordinating engagement?
- Is there sufficient time built into the timeline for ongoing collaboration?



Knowledge and Skills^{6,7}:

- Does the team have experience with youth engagement or participatory approaches? Do team members have experience working with diverse youth partners?
- Are there knowledge gaps (e.g., anti-oppressive practice, accessibility, trauma-informed approaches) within the team related to engagement? How will these gaps be addressed?
- What training is available to staff to support their growth and development?
 - See [Training for Research Staff](#) to learn about available training



Funding and Logistics^{6,7}:

- Is there a budget for honoraria, transportation, meals etc?
- Are logistics in place to support participation (e.g., scheduling, materials, interpretation)?
- Has the team considered barriers such as caregiving responsibilities, internet access, travel considerations, or geographic isolation?
- Does the team have contingency plans for unexpected costs or delays?



Institutional and Ethical Considerations^{6,7}:

- Has the team identified potential institutional or Research Ethics Board (REB) barriers to youth engagement?
- Has the team considered protections for youth partners sharing lived experiences or participating in emotionally charged discussions?
- How can youth communicate compliments or concerns about their engagement experience?
- See [Ethics in Engagement](#) to learn more about ethical considerations



Partnership and Relationship Culture^{6,7}:

- Are youth partners' voices valued equally to academic or clinical voices within the research team?
- How will the team address conflict, power imbalances, and/or communication barriers?
- How does the team plan to evaluate how youth partners' experience their involvement?
 - See [Step 9: Evaluation](#) to learn about evaluation



The [Office of Engagement](#) provides consultations to support engagement efforts, identify engagement opportunities within research projects, and develop engagement plans.



STEP 2: RECRUITMENT

Strategies to recruit youth partners may need to be extended beyond usual methods, such as leveraging partners within your research project. Additionally, connecting and collaborating with organizations and communities that presently engage with youth can help to recruit youth partners.



Before You Recruit Youth Partners⁸

- Promote inclusion of diverse youth partners by identifying and prioritizing underrepresented groups in research early
- Partner with youth-serving organizations and community groups
- Reach youth beyond typical networks, including those not connected to school, clinics, or social media
- Remove barriers to engagement by adapting recruitment methods (e.g., no previous experience)
- Plan recruitment intentionally and early to avoid tokenistic engagement, especially when working with underrepresented communities



Application Process- Guidelines

- Define recruitment criteria **clearly** in all materials, including:
 - Purpose and brief project overview
 - Eligibility (age range, province/territory, identities/lived experiences, perspectives needed)
 - Time commitment
 - Deadline for expressions of interest
 - Whether honoraria/recognition is provided for contributing
- Ensure flexibility to accommodate different communication styles and abilities
- Clearly outline the selection process including the adjudication matrix to manage expectations



Application Process- Forms

- Use simple, accessible platforms (e.g., REDCap, Google/Microsoft Forms). Forms should include:
 - Preferred name (also known as name in use), pronouns and preferred contact method
 - Interest in the project and any relevant experience
 - Optional demographic questions (only if necessary and with minimal burden)
- Use open-ended and reflective questions to understand fit and lived experience
- Offer applicants the option to complete the form with a staff member if needed
- If appropriate, offer multiple application formats such as written submissions, video responses, phone calls etc.



Recruitment Materials

- Ensure that the recruitment materials is accessible and developmentally appropriate⁶
- Consider involving youth in co-developing recruitment materials if you already have youth partners in your research program
- Visit [Recruitment Poster Design Considerations](#) for tips on how to make your recruitment poster accessible



The [Office of Engagement](#) can recruit youth for engagement opportunities from their Lived Experience Network (~200 advisors).



STEP 2: RECRUITMENT

Interviews with youth partners should be conducted in a supportive and youth-friendly manner. Interviews should include sharing key details about the opportunity, clearly outlining project expectations, and exploring alignment with the youth's interests. Framing the conversation this way helps ensure youth feel respected, informed, and empowered to engage as partners.



Interview Process- Scheduling

- Interviews can be conducted in-person, by phone, or virtual (e.g., Zoom, Teams, Google Meet)
- Plan for flexible interview scheduling to accommodate for school or personal schedules
- Use scheduling tools (e.g., Doodle, Calendly) to streamline booking
- Consider who conducts outreach:
 - Youth partners may find contact from Principal Investigators (PIs) intimidating. When possible, initial outreach should come from coordinators, assistants, or dedicated youth-engagement staff
 - If recruitment occurs through clinics or clinicians, manage conflicts of interest. *The outreach person should not also be the youth's clinician*



Interview Process- Interview

- The goal of the interview process is to explore the youth partner's alignment with the project and how their lived experience will contribute to the project
- Keep interviews brief (≤ 30 minutes), in plain-language
- During the interview, focus on:
 - Youth partner's lived experiences relevant to the project
 - Motivation, interests, expectations, and hopes



Interview Process- Follow-Up

- Give youth time to reflect on the opportunity (2 weeks)
- Research teams should be transparent about the outcome with the youth



Preventing Fraudulent Applicants

- [University of Toronto Tip Sheet](#) has information on preventing fraudulent applicants
- Add reCAPTCHA to your application forms
- Include questions such as "are you a bot" or other type of question, such as basic mathematical questions⁹



This step outlines how to onboard youth partners into research projects at SickKids. A structured and intentional onboarding process supports equity and comfort, and sets clear expectations for youth partners.



Determine Youth Partner Classification

- **Honoraria Recipients**
 - May not require full SickKids onboarding
 - See [Step 7: Compensation/Recognition](#) for details
- **Casual Employees or Trainees** may require onboarding through Human Resources (HR), Occupational Health and Safety (OHS), and training modules:
 - **HR:** Offer letter, personal information form, orientation, vulnerable sector screening, RTC registry, student hiring questionnaire, enrolment verification, work/study permits tax forms, direct deposit, Social Insurance Number (SIN) (if applicable)
 - **OHS:** Immunization requirements, TB testing, possible onsite visit
 - **Training:** iLearn modules



SickKids Building Access

- **If youth are onsite but not employees/trainees:**
 - Ensure youth's accessibility needs are met when visiting onsite (e.g., ensuring access to accessibility elevators)
 - Coordinate with Security for building or visitor access
 - Provide clear instructions (map, room number, point of contact)
- **Supporting Youth Who May Be Uncomfortable On-Site**
 - Always offer virtual or neutral location alternatives
 - Avoid making in-person attendance required for participation or payment
 - Normalize opting out: "Some youth find hospitals stressful. Tell us what feels right for you"
 - Offer hybrid or written/async options



Loop in HR and your lab administrator early to avoid delays



Send a welcome email with day-of guidance and contact details



Introduce the Research Team

- Provide a short document or slide with:
 - Names, roles, and contact info of team members
 - Who youth should contact for logistics, support, or research questions
 - Team structure



Research Project Overview

- Provide a youth-friendly summary that includes:
 - What the research project is about
 - Why youth are involved in the project
 - Project timelines
 - Anticipated outcomes of the research



Early introductions help build trust and comfort



Use visuals or analogies and plain-language when possible





Project Goals and Expectations for Engagement

- Communicate clearly with youth about:
 - How they will contribute (design input, reviewing materials, KT activities)
 - How their input will be used
 - Any limits related to timelines or budget
- Clarify mutual expectations around:
 - Frequency and format of engagement
 - Types of contributions (feedback, co-design, co-authorship)
 - How youth can opt in/out at any time
 - Supports provided (accessibility, updates)



Access to Technology and Tools

- Ensure youth have access to the following:
 - Shared drives/folders
 - Meeting platforms (Zoom, etc.)
 - Email updates or communication tools
- Avoid tools requiring institutional logins
- Ask youth partners about their preferences
- Look into institutional and team policies about what platforms/technology/tools to use



Conduct a brief tech walkthrough at the first meeting



Use a [Terms of Reference](#) to outline roles, co-create expectations and revisit regularly with youth partners



Remuneration

- Budget for honoraria/stipends early
- Use fair rates (hourly, per-meeting, or milestone-based)
- Clarify payment process, timelines, and required documents
- See [Step 7: Compensation/Recognition](#) for more details



Communicate expected payment timelines and a contact for questions

REMEMBER!

- Engage youth with flexibility, humility, and responsiveness
- Build relationships. Trust enables meaningful contributions
- Avoid assumptions about research experience
- Invest in onboarding and capacity-building
- Keep communication open with check-ins and feedback loops



The [Office of Engagement](#) can support the onboarding of youth partners and ensure meaningful engagement.

STEP 4: COLLABORATION

Engagement methods may differ depending on whether the research project is occurring in person or virtually. Research staff should be intentional in selecting and adapting engagement tools to support comfort, accessibility, and meaningful participation in each setting. Refer to the following chart for a comparison of in-person and virtual approaches:

Activities	In Person ^{8,10,11}	Virtual ^{8,10,11}
RELATIONSHIP BUILDING	<ul style="list-style-type: none">• Ice-breakers• Unstructured free time• Shared group activities (e.g. games, meals)	<ul style="list-style-type: none">• Icebreakers• Virtual check-ins• Polls (e.g. Mentimeter, Slido, Wooclap)• Breakout rooms
MAINTAINING RELATIONSHIPS	<ul style="list-style-type: none">• In person catch-ups• Team building activities• Retreat events	<ul style="list-style-type: none">• Group communication platforms (e.g. WhatsApp, Slack)• Online group activities (e.g. team building, skill building)
CO-CREATION	<ul style="list-style-type: none">• Posters, sticky notes, storyboards• Small group discussions, sharing circles• World cafes, concept mapping• Leadership roles (e.g. note taker, co-chair meetings)	<ul style="list-style-type: none">• Multi-media sensory tools (e.g. Miro, Mural, Zoom Jamboard)• Virtual sharing circles, World cafes concept mapping• Leadership roles (e.g. note taker, co-chair meetings)
DECISION-MAKING	<ul style="list-style-type: none">• Consensus circles• Ranking exercise• Dot voting• Concept mapping	<ul style="list-style-type: none">• Zoom polls, Google forms, Redcap surveys• Mentimeter• Collaborative Document• Collaborative voting tools (e.g. Mural, Miro)
FEEDBACK AND REFLECTION	<ul style="list-style-type: none">• Anonymous feedback boxes• Sticky notes on a feedback poster• 1-1 debriefs	<ul style="list-style-type: none">• Anonymous forms (e.g. Google forms, Redcap)• Group reflections in breakout rooms• Group reflections using interactive tools (e.g. Mentimeter)
KNOWLEDGE TRANSLATION	<ul style="list-style-type: none">• Co-presenting at conferences• Art-based methods (e.g. art installations)• Youth led panels/summit	<ul style="list-style-type: none">• Co-presenting at webinars• Designing youth friendly materials (e.g. infographics, zines)• Social media posts

STEP 4: COLLABORATION

When working with youth, research team members must be intentional about building rapport to foster reciprocal trust within the partnership. The following considerations can help ensure that young people are meaningfully engaged and feel valued in your project.



Develop Rapport^{7,8,12}

- Authentic relationships build trust and support meaningful engagement
 - Start with human connection. Learn youths' interests and preferred forms of address
 - Show consistency by following through on commitments
 - Demonstrate humility. Acknowledge mistakes and model repair
 - Offer mentorship and skill-building opportunities
- Youth engagement requires intentional rapport-building and reciprocal trust



Address Power Imbalances¹¹

- Power dynamics exist and must be actively minimized
 - Name power imbalances openly and normalize discussion
 - Set shared expectations and involve youth in decision-making
 - Avoid tokenism. Ensure youth contributions influence the project
 - Offer multiple, low-stakes ways to raise concerns (e.g., anonymous surveys, youth co-chair)
 - Reflect on your own power, privilege, and biases
 - Recognize, compensate, and value youth contributions consistently
 - Encourage research teams to use first names instead of titles to create a more welcoming, less formal environment
 - Avoid introductions that emphasize academic or professional roles or accomplishments



Anticipate and Remove Barriers^{8,10}

- **Capacity & Competing Priorities**
 - Youth may have school, work, family or other commitments
 - Check in regularly and adapt expectations when needed
 - Be flexible with timelines and engagement levels
- **Logistical Barriers**
 - Offer flexible meeting times (evenings/weekends across time zones)
 - Provide multiple ways to contribute (shared documents, asynchronous feedback)
 - Choose accessible virtual and physical meeting spaces
 - Consider additional burdens for in-person meetings (travel, meals, lost wages)
- **Funding**
 - Meaningful engagement requires adequate resources
 - Budget early for staff time, honoraria, accessibility supports, and engagement activities
 - Offer flexible payment options and communicate any delays promptly





Communicate Clearly and Accessibly¹⁰

- Use clear, direct, youth-friendly language and avoid jargon or acronyms
- Speak with youth rather than at them, balancing professionalism with warmth and approachability
- Be mindful of tone, pace, body language and offer full attention by minimizing distractions
- Use intentional relationship-building strategies (e.g., informal icebreakers) to foster comfort and trust
- Share materials in advance (e.g., slides, questions, glossaries) to support preparation
- Provide a clear overview of the project, roles, timelines, and expectations.
- Offer flexible and youth-preferred communication formats (e.g., WhatsApp or Slack instead of email)
- Reinforce key information and timelines throughout the engagement process
- Close the communication loop by sharing updates, decisions, and next steps, and acknowledging youth contributions
- Support youth who use assistive technologies or alternative communication methods
- Offer language interpretation as needed (e.g., ASL, Deaf interpretation, community-based services)
- Apply **Equity, Diversity, Inclusion, Anti-racism (EDI-AR)** and trauma-informed communication principles throughout
- Be transparent with youth partners if there are any delays in the project



Build Strong Check-In Practices⁸

- Check in on the process, communication and generally how things are going
- Regularly check for understanding and create space for questions
- Offer multiple, low-stakes ways to raise concerns (e.g., anonymous surveys, youth co-chair)
- Offer additional touchpoints outside formal meetings for questions or reflection
- Establish processes for youth partner to give research team feedback
 - Demonstrates humility and develop plans to address concerns
 - This can include a research team member, third party person or the **Office of Engagement**
- **For Research Staff**
 - Model openness and non-defensiveness
 - Use supportive, structured constructive feedback
 - Ask youth how they prefer to be check-in on the process (written, verbal, 1:1)
 - Encourage youth to ask questions, and request feedback on their contributions
 - Affirm that their perspectives have impact and value



The **Office of Engagement** can provide resources, and tools to support meaningful collaboration.



STEP 5: TRAINING

This step outlines how to plan, tailor, and deliver training for youth partners along with relevant resources. Training needs will vary depending on the level and type of engagement, research methods and stage of research.



Project Orientation:

- Overview of the research project and youth's role
- Timeline, logistics, and expectations
- Key team members and contact information



Research and Data Collection Methods:

- **General Research Process:** How does research work? What is the research process?
 - [Patient-Oriented Research Curriculum in Child Health \(PORCCH\) Modules](#)
 - [Study Designs: Centre for Evidence-Based Medicine- University of Oxford](#)
 - [Types of Research Methods \(YouTube Video\)](#)
- **Qualitative Methods:** How interviews/focus groups work, note-taking, probing tips, qualitative data analyses
 - [YouthREX – Facilitating Anti-Opressive Focus Groups \(PDF\)](#)
 - [Qualitative Study](#)
- **Quantitative Methods:** Basic surveys, concepts of reliability/validity, quantitative data collection and analyses
 - [Cheat Sheet for Statistics 101](#)
- **Reading Scientific Papers:**
 - [How to read a scientific paper](#)
 - [Additional Resources for Reading Academic and Scientific Papers](#)



Research Ethics Training:

- [TCPS 2: CORE-2022 \(Course on Research Ethics\)](#)
 - *Disclaimer: This is a requirement for youth who are formally onboarded as study team members who will be handling or collecting patient data. This course may not be youth friendly.*



Patient and Youth Engagement:

- **What is Patient Engagement/Youth Engagement**
 - [PORCCH Modules Patient Engagement 101](#)
 - [FER Youth Engagement Course](#)
 - Youth with lived experience can complete the course for FREE!



Knowledge Mobilization:

- **Co-authorship, what it means, what's expected**
 - [Writing Scientific Manuscripts](#)
 - [A Guide to Writing a Scientific Paper: A Focus on High School Through Graduate Level Student Research](#)
- **Sharing results on social media, podcasts, infographics**
 - See [Step 8: Knowledge Translation](#) for more information about knowledge mobilization/translation



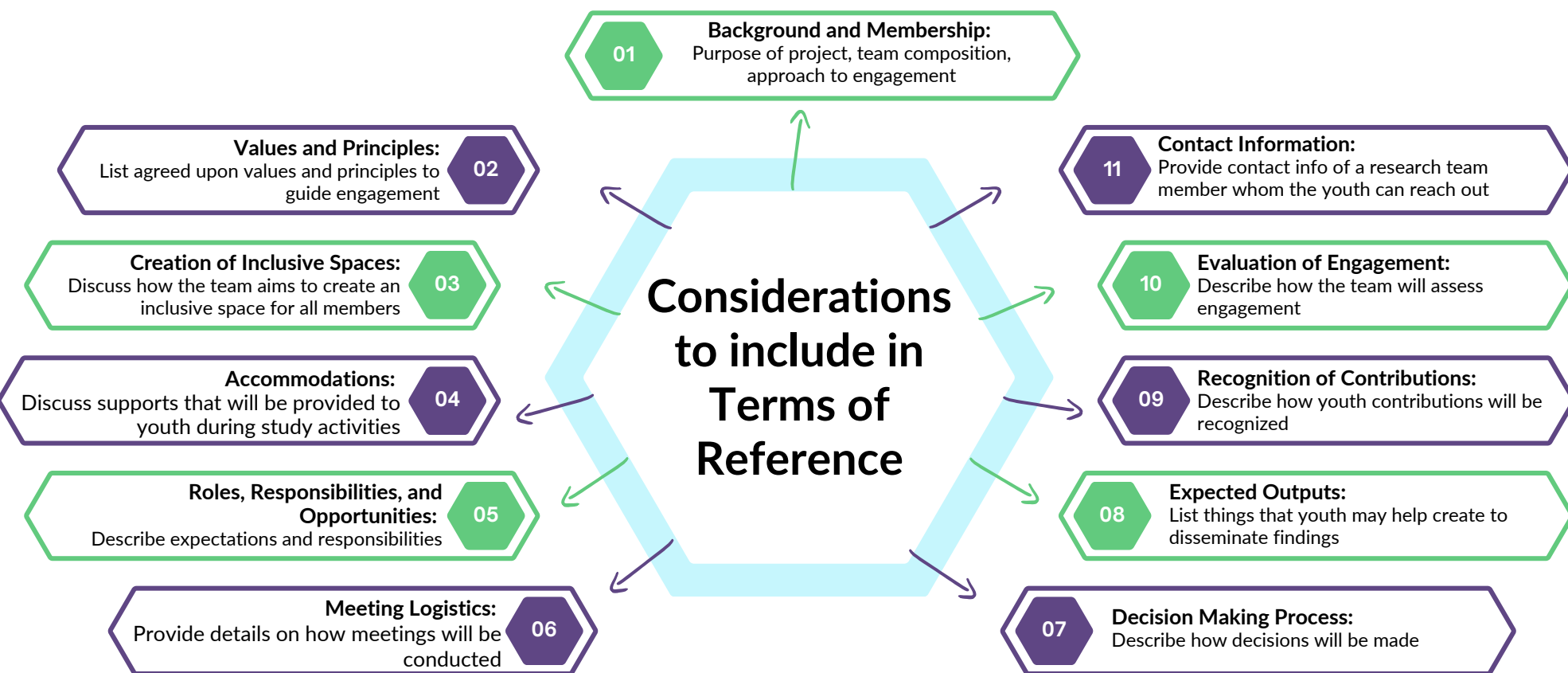
- Provide training before youth do the work
- Tailor training to project needs and youth's role in the project
- Ask youth if they would like additional training over the course of the study



STEP 6: ESTABLISHING EXPECTATIONS

When engaging youth in research, it's important to build a shared understanding of how everyone will work together. Clear expectations help youth feel respected and confident to contribute, and ensure the team and youth agree on roles, communication, decision-making, and support. A **Terms of Reference (ToR)** can support this.¹³

A ToR is a living document that outlines how youth and the research team will collaborate.¹³ It explains the purpose of the partnership, expectations, decision-making processes, and available supports.¹³ The ToR should be co-developed, written in plain language, and reviewed regularly as the project evolves.¹³ Below are key considerations to include in your ToR, which can be adapted to your study's needs. **An editable ToR template can be found [here](#).**



STEP 7: COMPENSATION/RECOGNITION

Youth bring lived experience and expertise to research. Recognition should be meaningful, flexible, and aligned with institutional policies. Youth should have agency in choosing how they would like to be recognized.¹⁴

Prioritize monetary compensation and consider non-monetary recognition.

Monetary Compensation¹⁵

- **Eligible Activities for Compensation**
 - Preparation time (reviewing materials, training, onboarding)
 - Participation in meetings, workshops, asynchronous activities etc.
 - Accommodations: transportation, childcare, meals, etc
- **Payment Guidelines**
 - Provide compensation promptly after each activity
 - Use the [SPOR Compensation Policy](#) as a reference
 - Adjust compensation based on level of engagement, task type, and project expectations
- **Payment Formats**
 - Gift cards are a common form of compensation. Consider asking preferred vendor or use flexible options like an [Everything Card](#)
 - Cheque requisition possible at SickKids [via MyFinance](#)
- **Institutional Requirements**
 - Some payment types may require onboarding youth as vendors/consultants, casual employees, or trainees
 - Social Insurance Numbers (SINs) may be required for cheque requisition. Discuss comfort and alternatives with youth in advance
- **Tax Considerations**
 - Honoraria ≥ \$500/year may be considered taxable income
 - This may affect youth receiving financial or disability supports (e.g., Ontario Disability Support Program (ODSP))
 - See [Canadian Revenue Agency \(CRA\) guidelines](#) for more details
 - Refer to [Step 3: Onboarding](#) for specifics on onboarding youth as vendors, consultants, or trainees.

Non-Monetary Recognition¹⁴

- **Ask Youth About Preferences First**
 - Provide options at the outset and ask if they have other ideas or needs
- **Academic Recognition**
 - Authorship or acknowledgements on publications, presentations, posters, or social media
 - *Permission must be obtained, as not all youth may want authorship, and some may prefer to remain anonymous to maintain their privacy*
- **Professional and Skill Development**
 - Volunteer hours
 - Course credit, where applicable
 - Research skills training (e.g., data collection, methods, analyses, KT)
 - Mentorship and coaching
 - Reference letters
 - Resume and portfolio development
- **Growth Opportunities**
 - Attendance at conferences, workshops, webinars, or training events
 - Networking opportunities with researchers, clinicians, other youth
 - See [Step 8: Knowledge Translation](#) for guidance on co-designing KT products and managing authorship preferences

STEP 8: KNOWLEDGE TRANSLATION

This step provides guidance for engaging youth in knowledge translation (KT), including dissemination, authorship, and reporting. Youth engagement in KT not only amplifies the impact of research findings but also supports capacity-building for youth partners.^{16,17}



Dissemination Planning

- Involve youth partners early in identifying dissemination goals and audiences
- Ask youth how they want findings shared (e.g., infographics, zines, social media, videos, podcasts, workshops)
- Co-create outputs that reflect youth priorities and lived experience
- Use dissemination formats and platforms that youth already use and trust
- Budget for youth led-dissemination activities



Presenting at Conferences

- Invite youth partners to co-present at conferences, workshops, or webinars
- Provide support with presentation preparation and public speaking (e.g., practice sessions, slides)
- Cover all costs associated with presenting (registration, travel, accommodation, meals, accessibility needs)



Reporting Engagement in Publications

- Use reporting guidelines (e.g., [GRIPP2](#)) to describe youth engagement in your publication
- Clearly describe how, when, and to what extent youth were engaged
- Outline the impact of youth contributions on the research project



Manuscript Contributions

- Invite youth to contribute to manuscript sections that interests them (e.g., plain-language summary, discussion).
- Provide editorial support, mentorship and training to youth unfamiliar with academic writing
- Consider including youth-authored reflections
- Clearly communicate to youth how their contributions are shaping the manuscript
- Allocate time for youth to review drafts and provide feedback
- Discuss alternative formats (e.g., creative writing, commentary boxes, arts-based methods) to reflect youth voices




Authorship on Publications

- Discuss authorship expectations early and transparently
- Recognize youth contributions equally to other team members
- Offer youth the choice to be listed as co-authors and ensure they are aware of the implications of being a co-author by name in a research paper (e.g., public disclosure of a health condition)
 - Reassess if youth want their name attached to the work or not if they are collaborating for a longer period of time. This can change depending on what stage of their disease/career/relationship with disease they are
- Offer youth the choice of using a pseudonym if they are not comfortable being publicly identified in publications
- Document and revisit authorship decisions throughout the project



STEP 9: EVALUATION

Evaluating your engagement efforts is essential to improve ongoing engagement practices and ensure youth voices are respected, heard, and effectively integrated into research projects. A combination of informal and formal methods for evaluation can be helpful, while also meeting the requirements of research teams, youth partners, and funding bodies.^{6,18,19,20}



When to Conduct Evaluations?

Beginning

- Baseline expectations

Mid-Point


- Process check-in

End of Project

- Overall Satisfaction
- Lessons Learned


Ongoing

- If youth are deeply engaged over a long time



Who Should Conduct Evaluations?

- A **team member** not involved in day-to-day youth engagement
- A **youth partner** with support, if peer-led feedback is preferred
- A **third-party evaluator**
 - **Office of Engagement**




How to Conduct Evaluations?

Informal Methods

- Regular verbal or written check-ins
- Anonymous feedback forms or brief surveys
- Reflective memos

Formal Methods

- Interviews and Focus Groups
- Questionnaires
 - **PEIRS-22**
 - **PPEET**



QUICK TIPS

TIPS TRICKS

- Co-develop evaluation questions with youth
- Ask youth how they would like to share their feedback at project outset
- Ensure evaluations are accessible (language, time, technology)
- Allow anonymous responses if preferred
- **Close the loop:** Share how youth feedback was used



The **Office of Engagement** can support research teams evaluate their engagement approaches.



Questionnaires may not be youth-specific and thus may not be developmentally appropriate!



[Return to Roadmap](#)



[Additional Resources](#)



[Next Section](#)



EQUITY, DIVERSITY, INCLUSION, AND ANTI RACISM

Meaningful youth engagement must be grounded in EDI-AR principles. This means creating safer, inclusive spaces where diverse youth can participate as equal partners and where structural inequities are actively addressed, not reinforced. Research staff are encouraged to seek additional support from individuals with academic, professional, or lived expertise in these topics.



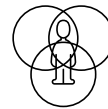
Anti-Oppressive Practice²¹

- Address inequities identified through intersectional reflection
- Challenge harmful norms and structural barriers that appear in the project
- Create accountability within the team for inclusive practices
- Encourage shared power and transparent communication
- Build shared decision-making into your processes by clearly outlining how decisions are made, being transparent about how input is used, and explaining when and why suggestions are not included



Cultural Safety & Humility²²⁻²⁵

- Recognize power imbalances between youth and researchers
- Understand how racism, colonialism, and bias shape engagement
- Reflect on your own assumptions, privilege, and positionality
- Share power with youth through openness and reciprocal learning



Intersectionality²⁶⁻²⁹

- Youth hold multiple, intersecting identities that shape experiences
- Avoid tokenizing one youth as the “representative” of a community
- Reflect on staff positionality and how it affects decision-making
- Consider context (space, culture, time) when engaging youth
- Allocate resources and funding for youth with more complex accessibility needs and tailor engagement methods accordingly (e.g., communication, sensory needs)



Trauma-Informed Approaches³⁰⁻³³

- Recognize that youth may carry trauma related to discrimination or past experiences; prioritize emotional, cultural, and physical safety
- Offer choice, flexibility, and shared decision-making
- Be transparent about processes, roles, and expectations
- Ensure culturally safe supports and referral pathways are available if distress arises
- Have support systems in place before, during, and after engagement activities
- Avoid extractive storytelling or tokenizing lived experiences, which can negatively impact youth relationships with research

EQUITY, DIVERSITY, INCLUSION, AND ANTI RACISM

Here are some tips when engaging with diverse youth:

Working with 2SLGBTQIA+ Youth³⁴

- Affirm identities through inclusive language and pronoun use
- Provide gender-neutral physical and virtual spaces
- Avoid outing youth. Allow them to share what they choose
- Correct misgendering calmly and without drawing attention
- Recognize that not everyone is comfortable sharing pronouns

Working with Youth from Rural Communities

- Rural youth may face limited opportunities and access barriers
- Recruit intentionally from rural organizations and online platforms
- Offer flexible participation (phone-in, hybrid, low-bandwidth options)
- Support access to stable technology or community spaces
- Budget for travel and logistical needs when in-person participation is required

Working with Youth from Racial/Cultural/Ethnic Minority Backgrounds³⁶

- Build trust by acknowledging cultural contexts and potential past harms
- Use inclusive, culturally appropriate language and offer translation if needed
- Be transparent about how their input will be used and valued
- Reduce barriers to participation (e.g., flexible timing, compensation, accessible formats)

Working with Indigenous Youth

- Build relationships early with youth, Elders, and communities
- Engage Indigenous youth before project planning begins
- Ensure reciprocity, not transactional engagement
- Support self-determination, choice, and informed consent
- Follow Indigenous data sovereignty principles
 - [Ownership, Control, Access, and Possession \(OCAP\)](#)

Working with Youth with Disabilities³⁵

- Recognize both visible and invisible disabilities
- Apply universal design: accessible platforms, plain language, multiple formats
- Ask youth about access needs, don't assume
- Respect health-related limits and flexibility
- Use a biopsychosocial, not deficit-based, view of disability
- Consider support persons and service animal needs



The [Office of Engagement](#) can provide support for youth partners.

TRAINING FOR RESEARCH STAFF

This section outlines training resources for researchers and research staff to support skill-building, meaningful partnerships, and inclusive research practices.



Courses and Modules

- [Patient-Oriented Research Curriculum in Child Health Modules](#)
 - 5 online modules (each module takes ~ 30 mins to complete)
 - Free!
 - Can be completed by anyone interested in learning more about patient-oriented research
- [Family Engagement in Research- Youth Program](#)
 - Family Engagement in Research Program at McMaster University
 - 10 week online course
 - Approximately \$800
 - Follow them on Instagram [@ferprogram](#) for updates



Webinars and Presentations

- [Establishing Meaningful Advisory Committees](#)
- [Ethical Considerations for Collaborating with Patient and Community Partners in Research](#)
- [Planting the Seeds of Sustainable Youth Engagement in Research](#)
- [Engaging the Community in Research: Insights from Youth Partners](#)
- [Community-Based Research: Preparing Your Study for REB Submission](#)
- [Partnering with Youth and Parents on Your Pediatric Research Grants: From Conceptualization to Submission](#)



The [Office of Engagement](#) can support training research teams on engagement.



The Community Engagement Series at the Edwin S.H. Leong Centre for Healthy Children hosts virtual 1 hour sessions on best practices for community engagement, including youth engagement. Click [here to sign up](#) or [here to learn more](#)



Engaging youth during grant development helps ensure research priorities, questions, and methods reflect what matters most to young people, while strengthening proposals through authentic partnerships. This section outlines how to involve youth, required documents, and key considerations for incorporating youth engagement into grant applications.

Youth Roles in Grant Applications

Here are common roles youth can take on grant applications:



The [Office of Engagement](#) can support grant applications, including budgets, engagement plans etc.

Knowledge Users

- Youth provide lived-experience insights that inform decisions, policies, and KT activities
- They may:
 - Advise on youth-friendly KT and dissemination
 - Support evidence-informed program/policy development
 - Mobilize findings through youth networks

Collaborators

- Youth provide specific expertise or perspectives to support the research
- They may:
 - Provide subject-matter expertise
 - Support and advise on discrete research activities (e.g., recruitment, analysis)
- *More intensive and ongoing involvement than Knowledge Users*

Co-Applicants

- Youth are part of the research team throughout the project
- They may:
 - Help with recruitment
 - Provide input on engagement strategies
 - Interpret findings
 - Co-create KT products
- *More intensive and ongoing involvement than Knowledge Users and Collaborators*

Co-Principal Applicants

- Youth help steer the direction of the research
- They may:
 - Identify priorities and outcomes
 - Co-design methods, recruitment, data collection, and KT plans
- *Highest-intensity role; requires substantial time commitment*



QUICK TIPS

- Youth may require CIHR PINs or SSHRC CID numbers
 - Provide guidance as youth may not be familiar with these processes and terms
- Take the time to explain to youth their role is on the grant, expected time commitment and that participation is contingent upon a successful application process

Common documents that are required during grant applications are letters of supports and CVs. Here are some tips:



Letters of Support

- Youth partners may need to provide a letter depending on their role and the grant call requirements
- While requirements of letters of support may vary, a Letter of Support typically includes:
 - Who they are (their lived expertise) and their connection to project
 - Why the project matters to them/community
 - Their role in the project and contributions
 - Expected time commitment, if funded
 - How this experience supports their goals



Curriculum Vitae (CV)

- Some grants require youth to create a Curriculum Vitae (CV). Grants often provide a template or reference common templates such as the [NIH Biosketch](#) or, [Tri-Agency Narrative CV](#), but these templates are typically designed for researchers and not youth partners
- Youth partners can include the following in their CVs
 - Lived experience
 - Volunteer roles
 - Employment history
 - Advocacy and/or community work
 - School work
 - Past engagement work



QUICK TIPS

- Provide templates of Letters of Supports or co-write with youth when needed
- If you have other youth partners who have experience drafting CVs for grants, pair youth partners with a more experienced youth partner as a “writing buddy”

Here is some language that you can use when describing your engagement approach in your grant applications and budgets:

Integrating Youth Engagement Into Your Grant Proposal⁶

- **Rationale**
 - Explain why youth engagement is essential.
 - Sample wording:
 - *Ensures research reflects youth priorities*
 - *Improves relevance, feasibility, and impact of findings*
 - *Supports more meaningful interventions and policies*
- **Engagement Plan**
 - Describe when, how, and to what extent youth will be engaged. Include any structured approach such as a patient engagement model, theory or framework.
 - Could be a separate section or part of methods of grant proposal
 - Sample wording:
 - *“Youth will be engaged as partners, not just participants.”*
 - *“Youth will co-develop study materials and shape KT activities.”*
- **Past Success**
 - Highlight prior youth engagement experience (if applicable) and how your team will leverage that.

Budget Justification for Youth Partners⁶

- Include specific roles, rates, hours, and benefits.
 - **Examples**
 - **Youth Advisors**
 - $X \text{ youth} \times Y \text{ hours/year} \times \$ \text{ rate (+ benefits)}$
 - **Activities:** advising on recruitment, reviewing materials, interpreting findings, KT support
 - **Youth Consultants**
 - $\text{Honorarium } \$XX \text{ per consultation} \times \# \text{ sessions} \times \# \text{ youth}$
 - **Activities:** study planning consultations, KT contributions
 - **Youth Research Staff**
 - $\text{Hourly rate} \times \text{hours/week} \times \text{duration} \times \text{benefits}$
 - **Activities:** co-develop materials, assist with recruitment, data collection, analysis, and youth-friendly KT products



QUICK TIPS

- See [Step 7: Compensation/Recognition](#) to learn more about monetary recognition
- Be specific when outlining the roles and responsibilities of youth partners in your budget justification, and include rates (e.g., how does it align with existing institutional, community or ethical guidelines)
- Plan for youth engagement early in your budget

Engaging youth partners requires careful attention to ethical principles, Research Ethics Board (REB) requirements, and protections around data, privacy, and power dynamics. Generally speaking, youth partners do not need outright REB approval. However, ethical principles still need to be adhered to. These tips help **maintain trust, safety, and respect** in all youth–research partnerships.

Youth Partners Do Need to be Added to eREB When Doing these Activities:

- Providing project advice (e.g., how to conduct the study)
- Co-designing materials (e.g., recruitment materials, data collection materials)
- Giving input on recruitment or dissemination
- Participating in advisory meetings
- Reviewing only summarized or anonymized data

Youth Partners Need to be Added to eREB When Doing these Activities:

- Conducting qualitative interviews
- Analyzing identifiable data (e.g., raw data)
- Accessing personal health information (PHI)
- As a result, youth may require:
 - Ethics training
 - [TCPS 2: CORE-2022](#)
 - Contracts or agreements
 - Confidentiality forms
 - Institutional onboarding (e.g., orientation, occupational health requirements, criminal record checks)

Avoiding Exploitation of Youth Partners

- Ensure youth are not asked to share personal experiences in ways that would make them feel uncomfortable or unsafe
- Youth should never feel pressured to disclose personal or traumatic information, especially in group settings
- Respect boundaries and provide space to opt out of any activity without needing to explain why



- Check in regularly with youth individually (this can be done informally)
- Avoid tokenism by ensuring youth have meaningful roles and influence on the conduct of the study
- Provide access to support resources (e.g., mental health or crisis lines) or individuals

Here are some sample language to include in eREB applications depending on your research project and the role of youth partners:

Description of Engagement:

- “This study includes the meaningful engagement of youth as research partners throughout the design, implementation, and dissemination of the research. These youth partners are not research participants (e.g., providing data), but collaborators who provide lived experience perspectives to inform the study.”

Examples of Youth Partner Responsibilities:

- Co-developing study materials (e.g., recruitment materials, interview guides)
- Advising on recruitment and knowledge mobilization strategies
- Participating in advisory or steering committee meetings to inform the conduct of the study
- Contributing to data interpretation by providing their lived expertise

Training:

- “Youth partners will receive an orientation and optional training tailored to their role.”
- “For those accessing anonymized data, an abbreviated training on confidentiality and ethical research practices will be provided. If required, youth partners may complete the TCPS 2: CORE-2022 modules”

Support and Risk Mitigation:

- Emotional safety will be prioritized through flexible participation, access to crisis lines, and accommodations for trauma-informed engagement.
- Youth partners can pause or withdraw from activities at any time without explanation.
- Youth partners can also reach out to neutral third party if support is needed such as the Office of Patient, Family and Community Engagement.



Consult [SickKids REB](#) early on to understand what is required for youth partners who will need to have access to participant data or PHI. This could include Data Transfer Agreements, but will be dependent on the context of your specific research study.

ADDITIONAL RESOURCES

Here are additional resources to support meaningful youth engagement. These resources include tools and tips:

Background

- [Designing a tool to support patient and public involvement in research projects: the Involvement Matrix](#)
 - This article discusses the development of the Involvement Matrix, a tool which can be used to discuss about possible roles of patient partner

Step 4: Collaboration

- [Challenges with online focus group](#)
 - This article reflects upon the challenges faced, and choices made, when conducting online focus groups with young people
- [With long meetings in both settings, consider implementing brain break](#)
 - This article discusses implementing brain breaks, which are quick structured breaks to refocus

Step 5: Training

- [Patients in Publication](#)
 - This is a course that trains patient advocates on how to engage in publications

Step 6: Establishing Expectations

- [Establishing Effective Patient Engagement Through a Terms of Reference to Foster Inclusivity and Empowerment in Research](#)
 - This article discusses how to create a terms of reference

Step 7: Compensation/Recognition

- [Considerations when paying patient partners in research](#)
 - This provides additional guidance related to compensation

Step 8: Knowledge Translation

- [Guidance on authorship with and acknowledgement of patient partners in patient-oriented research](#)
 - A paper on authorship with patient partners, including how they can meet authorship criteria, definitions of key publication terms, and a flowchart outlining the general steps in academic publishing.
- [Should I use a pseudonym?](#)
 - A resource for youth who decide to you a pseudonym when being listed as a co-author



ADDITIONAL RESOURCES

Step 8: Knowledge Translation

- **[How do I publish a paper? For publication teams including patient partners](#)**
 - A 4-minute video that covers what co-writing a paper with patient partners as authors might look like
- **[Menu of Knowledge Dissemination Approaches](#)**
 - A infographic outlining some common strategies you can use to share health research findings and activities with your intended audience to increase awareness and promote change
- **[Providing input on a research team's draft manuscript: Why this is important and some guidance](#)**
 - A resource for patient partners on providing input on a draft manuscript
- **[Asking patient partners/people with lived experience to provide input on a draft manuscript: Things to consider and some guidance](#)**
 - A resource for research teams about how to ask patient partners to provide input on a draft manuscript

Step 9: Evaluation of Engagement

- **[Centre of Excellence on Partnership with Patients and the Public- Evaluation Toolkit](#)**
 - This resource includes a range of tools to assist them in the evaluation of patient and public engagement initiatives, both in health research and in health care

Equity, Diversity, Inclusion, and Anti Racism (EDI-AR)

- **[Meaningful Engagement with Young Persons with Disabilities](#)**
 - This Guidance Note outlines strategies to create inclusive environments and ensure that the perspectives of young persons with disabilities are respected and actively considered
- **[Creating Inclusive Program Environments for Youth with Different Abilities: A Training Manual](#)**
 - This resource provide youth work professionals with information, practices, and activities that will help them promote inclusion and engagement for all young people

General Tools

- **[Passerelle Resources and Tools Repository](#)**
 - Includes a range of resources and tools for patient oriented research, such as good practices guides, planning tools and webinars

If you have additional questions about youth engagement, or have feedback about this roadmap, feel free to reach out to the Toulany Lab at toulany.lab@sickkids.ca or the Office of Engagement at ask.engagement@sickkids.ca

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