

Patient Engagement Resources

For Researchers

The ACT Patient Engagement Committee has curated a collection of resources from various Canadian organizations. These free resources include online courses, journal articles, toolkits, and more to help researchers and institutions implement best practices in patient engagement.

[Click here to register for CANTRAIN](#)

[Click here to register for IMPaCT](#)

Coming Soon!

Online Learning Modules

Common Core Foundation Level Program
Module 4: Patient Engagement in Research
Module 8: Participant Recruitment


[CANadian Consortium of Clinical Trial TRAINing Platform \(CANTRAIN\)](#)

[CIHR's Institute of Musculoskeletal Health and Arthritis \(IMHA\) Patient Engagement in Research](#)

[Increasing capacity for Maternal and Pediatric Clinical Trials \(IMPaCT\)](#)

[Patient-Oriented Research Curriculum in Child Health \(PORCHH\)](#)

Patient and Family Engagement in Trials
Module 1: [The how, when, and why of engagement in trials](#)
Module 2: [Engaging parents and pregnant people in clinical trials](#)
Module 3: [Engaging youth in clinical trials](#)
Module 4: [Best practices and resources for engagement](#)



Module 1: What is patient engagement?
Module 2: The research process
Module 3: Setting up a research project for successful partnership
Module 4: Patient engagement for research teams

Patient Engagement 101 (Part 1): Foundations of Patient Engagement
Patient Engagement 101 (Part 2): Patient Engagement in Practice

The ACT Patient Engagement committee is a group of researchers and patient partners dedicated to improving the patient engagement process in Canadian clinical trials. If you have any questions about how to best incorporate patient engagement in your clinical trials, please reach out to the committee at ACT.Canada@PHRI.ca.

Patient Engagement Resources



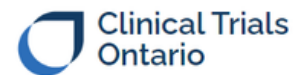
Handouts/Tip Sheets

- [Chairing Meetings with Patient and Caregiver Advisors](#)
- [Consumer and Community Participation in Health and Medical Research Fact Sheet Series](#)
- [Do's and Don't: Guidelines for Researchers, Patient Partners, and anyone new joining](#)
- [Family Engagement in Research Initial Meeting Guide for Research Partners](#)
- [IMAGINE Network Patient Partner Roles](#)
- [Onboarding Guide for New Patient-Oriented Research Teams](#)
- [Patient and Family Engagement in Trials Infographic](#)
- [Patient Compensation Guidelines](#)
- [Patient Partner Co-Application Guide](#)
- [Supporting Patients and Caregivers to Share Their Stories](#)
- [Take your patient partnering to the next level](#)
- [Tips for collaboration in patient engagement](#)
- [UK Standards for Public Involvement](#)
- [What to Include in a Call for Patient & Public Partners](#)
- [\[Fr\] Conseils à l'intention des chercheurs qui collaborent avec des patients partenaires](#)
- [\[Fr\]Conseils à l'intention des patients partenaires qui participent à la recherche axée sur le patient](#)
- [\[Fr\] Les 10 conseils sur l'engagement des jeunes dans la recherche](#)

Tools

- ["CHI Patient and Public Engagement Budget Builder"](#)
- [Patient Engagement in Research Scale](#)
- [Patient Engagement Planning Template](#)
- [Patient Partner Appreciation Policy and Protocol](#)
- [Patient-Oriented Research Pathways Self-Assessment Readiness Tool for Researchers](#)
- [PPI Planning Tool](#)
- [Preliminary Scoring Guide for the Patient Engagement in Research Scale](#)
- [Researcher Surveys – Evaluating the Patient Partnership in Research](#)
- [SCPOR Patient-Oriented Research Level of Engagement Tool](#)

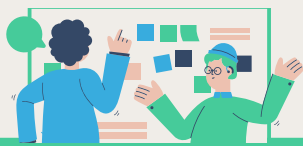
Resources have been selected from:



Patient Engagement Resources

Websites

- [Engagement in Health Research Literature Explorer](#)
- [Engagement Tool and Resource Repository](#)
- [NYAP & SibYAC's 10 Tips for Researchers](#)
- [Strategy for Patient-Oriented Research](#)
- [The Patient Experience Library](#)
- [\[Fr\] Passerelle](#)



Toolkits

Engagement in Research: Foundational Expectations for Partnerships	Ethics Guidance for Developing Partnerships with Patients and Researchers
Engaging Patients in the Research Process: A toolkit for project leads	Good Participatory Practice (GPP) for COVID-19 clinical trials: A toolbox
DIY Community Engagement Event Toolkit	Good participatory practice guidelines for trials of emerging (and re-emerging) pathogens that are likely to cause severe outbreaks in the near future and for which few or no medical countermeasures exist (GPP-EP). Outcome document of the consultative process.
Engaging People with Lived Experience in Research	
Participant Experience Toolkit	
Engaging your Community about Clinical Trials: A Toolkit for Organizations	How-to Guide on Patient Engagement in Clinical Trial Protocol Design
Patient Protocol Engagement Toolkit (P-PET) Resource Guide	Patient Protocol Engagement Toolkit (P-PET) User Guide
Research in Practice: Student Projects	Supporting equity-centered engagement: A step-by-step guide with tailored resources

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Patient Engagement Resources



Further Readings

- Bloom, D. J., Beetsch, J., Harker, M., Hesterlee, S., Moreira, P., Patrick-Lake, B., Selig, W., Sherman, J., Smith, S. K., Valentine, J.E., & Roberts, J. N. (2018). **The Rules of Engagement: CTTI Recommendations for Successful Collaborations Between Sponsors and Patient Groups Around Clinical Trials.** *Therapeutic Innovation & Regulatory Science*, 52(2): 206-213. <https://doi.org/10.1177/2168479017720247>
- Etchegary, H., Pike, A., Patey, A. M., Gionet, E., Johnston, B., Goold, S., Francis, V., Grimshaw, J., & Hall, A. (2022). **Operationalizing a patient engagement plan for health research: Sharing a codesigned planning template from a national clinical trial.** *Health Expectations*, 25(2), 697-711. <https://doi.org/10.1111/hex.13417>
- Foster, M., Fergusson D. A., Hawrysh T., Presseau J., Kekre N., Schwartz S., Castillo G., Asad S., Fox G., Atkins H., Thavorn K., Montroy J., Holt R. A., Monfaredi Z. & Lalu M. M. (2020). **Partnering with patients to get better outcomes with chimeric antigen receptor T-cell therapy: towards engagement of patients in early phase trials.** *Research Involvement and Engagement*, 6(61). <https://doi.org/10.1186/s40900-020-00230-5>
- Gamble, C., Dudley, L., Allam, A., Bell, P., Buck, D., Goodare, H., Hanley, B., Preston, J., Walker, A., Williamson P. R., & Young, B. (2015). **An evidence base to optimise methods for involving patient and public contributors in clinical trials: a mixed-methods study.** *Health Services and Delivery Research* 3(39): 1-142. <https://doi.org/10.3310/hsdr03390>
- Hamilton, C.B., Hoens, A.M., McQuitty, S., McKinnon, A.M., English, K., Backman, C.L., Azimi, T. & Khodarahmi, N. (2018). **Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective.** *PLoS ONE* 13(11): e0206588. <https://doi.org/10.1371/journal.pone.0206588>
- Levitan, B., Getz, K., Eisenstein, E. L., Goldberg, M., Harker, M., Hesterlee, S., Patrick-Lake, B., Roberts, J. N. & DiMasi, J. (2018). **Assessing the Financial Value of Patient Engagement: A Quantitative Approach from CTTI's Patient Groups and Clinical Trials Project.** *Therapeutic Innovation & Regulatory Science* 52(2): 220-229. <https://doi.org/10.1177/2168479017716715>
- Michaud, S., Needham, J., Sundquist, S., Johnson, D., Hanna, S., Hosseinzadeh, S., Bartekian, V., Steele, P., Benchimol, S., Ross, N. & Stein, B. D. (2021). **Patient and Patient Group Engagement in Cancer Clinical Trials: A Stakeholder Charter.** *Current Oncology* 28(2): 1447-1458. <https://doi.org/10.3390/curroncol28020137>
- Nicholls, S. G. & Campbell, M. K. (2024). **Embedding Patient and Health Care Professional Voices in Clinical Trials.** *JAMA* 332(5): 365-366. <https://doi.org/10.1001/jama.2024.6314>
- Schoemaker, C.G., Richards, D.P. & de Wit, M. **Matching researchers' needs and patients' contributions: practical tips for meaningful patient engagement from the field of rheumatology.** (2023). *Annals of the Rheumatic Diseases*, 82(3): 312-315. <https://doi.org/10.1136/ard-2022-223561>
- Selman, L. E., C. Clement, M. Douglas, K. Douglas, J. Taylor, C. Metcalfe, J. A. Lane and J. Horwood (2021). **Patient and public involvement in randomised clinical trials: a mixed-methods study of a clinical trials unit to identify good practice, barriers and facilitators.** *Trials* 22(1): 735. <https://doi.org/10.1186/s13063-021-05701-y>