

Learning Task 1.3:

PE, Clinical Trials, and POR: From the literature

- **Community members co-designing a trial of medication access. Persaud et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S44>
- **Patient engagement in a trial testing a new strategy of care for acute heart failure. Lee et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S34>
- **Patient and caregiver involvement in a multicentre clustered hemodialysis trial. Ward et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S32>
- **Patient engagement in research related to accelerated surgical care and treatment for hip fracture. McGillion et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S38>
- **Patient involvement in clinical trials: motivation and expectations differ between patients and researchers involved in a trial on urinary tract infections**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0145-3>
- **Involving seldom-heard groups in a PPI process to inform the design of a proposed trial on the use of probiotics to prevent preterm birth: a case study. J Rayment et al (2017)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0061-3>
- **Engaging parents to research childhood interventions aimed at preventing common health problems. Kim et al. (2018).**
 - <http://www.cmaj.ca/content/190/supplement/S22>
- **Patient engagement in pediatric concussion research. Reed et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S28>
- **Engaging patients to improve equitable access to community resources. Dahrouge et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S46>
- **Effectiveness of parents and clinicians working together to improve pain management in newborns. Harrison et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S26>
- **Describing the process of ethical conduct of research in an Ontario-wide First Nations diabetes research project. Walker et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S19>
- **Beyond the patient: lessons from community engagement in a rural First Nation. Young et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S16>

- **Patient and paramedic engagement in prehospital emergency medicine research. Vaillancourt et al. (2018)**
 - <http://www.cmaj.ca/content/190/supplement/S48>
- **Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch. Crow et al (2015)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0003-x>
- **From tokenism to meaningful engagement: best practices in patient involvement in an EU project. D. Supple et al (2015)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0004-9>
- **Facilitating non-tokenistic user involvement in research. Romsland et al. (2019)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0153-3>
- **Learning to work together – lessons from a reflective analysis of a research project on public involvement. A Howe et al (2017)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0051-x>
- **Exploring the motivations of patients with type 2 diabetes to participate in clinical trials: a qualitative analysis. S Estcourt et al (2016)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0050-y>
- **Keeping it credible in cohort multiple Randomised Controlled Trials: the Community Ageing Research 75+ (CARE 75+) study model of patient and public involvement and engagement. A Heaven et al (2016)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0044-9>
- **Including patients in core outcome set development: issues to consider based on three workshops with around 100 international delegates. B Young & H Bagley (2016)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0039-6>
- **A patient and public involvement (PPI) toolkit for meaningful and flexible involvement in clinical trials – a work in progress. P.R. Williamson (2016)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0029-8>
- **Practical considerations in improving research through public involvement. M.K. Jenner et al (2015)**
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0002-y>
- **Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. Harrison et al. (2019)**
 - <https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12873>
- **The importance of measuring the impact of patient-oriented research. D Aubin et al. (2019)**
 - <http://www.cmaj.ca/content/191/31/E860>
- **The PCORI Engagement Rubric: Promising practices for partnering in research. Sheridan et al. (2017)**
 - <http://www.annfammed.org/content/15/2/165.full>

- Twelve lessons learned for effective research partnerships between patients, caregivers, clinicians, academic researchers, and other stakeholders. Witteman et al. (2018)
 - <https://link.springer.com/article/10.1007/s11606-017-4269-6>
- Patient- and community-oriented research: How is authentic engagement identified in grant applications? Ramsden et al. (2017)
 - <https://www.cfp.ca/content/63/1/74>
- Involving young people in BRIGHTLIGHT from study inception to secondary data analysis: insights from 10 years of user involvement. Taylor et al (2018)
 - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0135-x>
- A Systematic Review of Stakeholder Engagement in Comparative Effectiveness and Patient-Centered Outcomes Research. T.W. Concannon et al (2014). Journal of General Internal Medicine
 - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4242886/>
- **The PCORI Engagement Rubric: Promising practices for partnering in research (Accès libre/Open access)** Sheridan et al. (2017) *The Annals of Family Medicine*
- **Changing what researchers' think and do': Is this how involvement impacts on research? (Accès libre/Open access)** K Staley (2017) *Research for All*
- Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: A UK-based qualitative interview study. J.C. Crocker et al (2016) Health Expectations
 - <https://www.ncbi.nlm.nih.gov/pubmed/27338242>
- How and why should we engage parents as co-researchers in health research? A scoping review of current practices. S. Shen et al (2016) Health Expectations
 - <http://onlinelibrary.wiley.com/doi/10.1111/hex.12490/abstract>
- Patient participation as an integral part of patient-reported outcomes development ensures the representation of the patient voice: a case study from the field of rheumatology. MPT deWit et al (2015). RMD Open
 - <https://rmdopen.bmj.com/content/1/1/e000129>
- The prevalence of patient engagement in published trials: a systematic review.
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/29796308>
- Patients driving the clinical trial designs - Democracy in clinical research.
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/31393256>
- Patient preferences for using mobile technologies in clinical trials.
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/31312746>
- Effective stakeholder engagement: design and implementation of a clinical trial (SWOG S1415CD) to improve cancer care.
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/31185918>

- **The importance of patient-reported outcomes in clinical trials and strategies for future optimization.**
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/30464666>
- **Engaging Stakeholders and Patient Partners.**
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/30213411>
- **A qualitative study of patients' perceptions of the utility of patient-reported outcome measures of symptoms in primary care clinics.**
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/30109471>
- **Choosing outcomes for clinical trials: a pragmatic perspective.**
 - <https://www.ncbi.nlm.nih.gov.ezproxy.lib.ucalgary.ca/pubmed/30074502>