

Session 3

How can patients be engaged in research?



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Objectives

- To gain knowledge and skills in engaging patients in research as study participants
- To gain knowledge about the challenges and benefits to various approaches to patient engagement in research
- To gain knowledge of how to assess validity of therapy studies

Exercise

- You are a physician seeing a patient who was just diagnosed with colon cancer.
- You have heard about a potential new treatment to consider and find there is a randomised trial that is testing this intervention.
 - How would you approach your patient to consider participating in this trial?
 - What challenges to engaging them in research might you expect?

Setting the stage

- <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/feelings-about-being-allocated-randomised-treatment-group>

Reasons why patients may want to participate

- <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/reasons-wanting-take-part-personal-benefit>

Perceptions of randomisation

- <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/feelings-about-being-allocated-randomised-treatment-group>

Importance of blinding

- <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/blinded-trials>

Patients as Partners/Advisors in Research

- The Canadian Arthritis Network-Consumer Advisory Council (CAC)
 - Representation on governing committees of Research Network
 - Representation on all conference/workshop planning committees
 - Mentorship of other patients/provision or professional development workshops for Council
 - www.arthritispatient.ca/research

Beyond the Canadian Arthritis Network

- Arthritis Research Centre of Canada's Patient Advisory Board – similar to CAC model
- Recently funded SPOR Chronic Pain Network
 - Included patient representatives from multiple patient organisations in grant application process
 - Will form a patient advisory council similar to the CAC model, with representation from patient organisations involved in application