

Appendix A: Resources

Links to Patient Engagement Tools – Arthritis Research Center of Canada

<http://www.arthritisresearch.ca/spring2016-news/interview-with-dr-linda-li>

<http://www.arthritisresearch.ca/spring2016-news/does-patient-engagement-in-research-matter>

The Canadian Arthritis Network

Video number 3 – Value of Consumers (Patients) in Research, The CAN experience

Video number 4 – Value of Collaboration and Partnership

<http://can.arthritisalliance.ca/en/video>

Presentations

Patient Involvement in Research

www.arthritispatient.ca/files/6114/0633/2547/Consumer_Involvement_in_research_FINAL_v9_March_23.pdf

Guides

Guide for Researchers and Consumers

http://www.arthritispatient.ca/files/5914/3881/7169/Guide_for_Researchers_and_Consumers.pdf

Papers

Consumer Impacts on Research at CAN

http://www.arthritispatient.ca/files/9014/3881/7205/Consumer_Impact_Paper.pdf

Consumers as Partners in Research Knowledge and Exchange

http://www.arthritispatient.ca/files/8814/3881/7247/KTE_Guide.pdf

The Arthritis Society – Consumer/Patient Involvement in Grant Reviews

<https://www.youtube.com/watch?v=KQQ1cMFWvHY&feature=youtu.be>

N2 – Participation in Clinical Trials

Developed by patients for patients

<http://itstartswithme.ca/>

Strategy for Patient Oriented Research

<http://cihr-irsc.gc.ca/e/45851.html>

SPOR Patient Engagement Framework

<http://cihr-irsc.gc.ca/e/48413.html>

Canadian Agency for Drugs and Technology in Health

Patient Input Process

<https://www.cadth.ca/about-cadth/what-we-do/products-services/cdr/patient-input>

Patient Centred Outcomes Research Institute

www.pcori.org/

healthtalk.org – Patient experience of health and engaging patients in research

<http://www.healthtalk.org/>

Informed Medical Decisions Foundation

<http://www.informedmedicaldecisions.org/>

NHS Shared Decision Making

<http://sdm.rightcare.nhs.uk/>

Patient Decision Aids (includes a tutorial for clinicians in shared decision making)

<https://decisionaid.ohri.ca/>

PACER – patient and community engagement research

<https://obrieniph.ucalgary.ca/pacer>

Mayo clinic SDM Resource

www.shareddecisions.mayoclinic.org

Dartmouth Centre for Shared Decision Making

http://med.dartmouth-hitchcock.org/csdm_toolkits/primary_care_toolkit.html

The Option Grids

<http://optiongrid.org/option-grids/current-grids>

Patient Involvement in Research

The Canadian Arthritis Network – Consumer Advisory Council

- **Membership on all Decision Making Committees**
- **Observer Status on governing Board of Directors**
- **Grant Review**
- **Collaboration with Trainees**
- **Conference planning and participation**
- **Knowledge Translation – Canadian Arthritis Networks – Canadian Arthritis Research Exchange Seminars - CAN CARES, Poster Development/Presentation, Papers, Guides**
- **Research Partners, input into direction, value to patients**
- **Letters of Support**