



GUIDE FOR RESEARCHERS AND CONSUMERS

CONSUMER INVOLVEMENT IN RESEARCH PROJECTS

Produced by the Consumer Advisory Council
of the Canadian Arthritis Network

This guide was developed by Louise Bergeron, CAPA Allied Member on the Consumer Advisory Council, Anne Dooley and all members of the Consumer Advisory Council. We thank Dr. Gillian Hawker and Melissa French, of Women's College Hospital in Toronto, for reviewing this material.



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This pamphlet is a guideline for both consumers and researchers on the issues that need to be discussed when involving a consumer as a team member on a research project

Before consumers and researchers agree to work together on a research project they must discuss and be in agreement on:

1. BASIC PROJECT INFORMATION

- **Project information:**
 - ✓ What is the project about/intent of the research?
 - ✓ Type of research, e.g. focus group, survey, etc.
 - ✓ Plain language summary

- **Principal Investigator's name and contact information**
 - ✓ Other investigators/researchers
 - ✓ Other consumers on project
 - ✓ Opportunity to ask questions – phone, email or interview

- **Location of research; multiple sites?**

- **Is research disease specific? Other disease specific requirements to be met by involved consumer?**

- **Time frame of project (e.g. six months, three years, etc)**

- **Required time commitment of consumer**
 - ✓ Dates, times and frequency of meetings/teleconferences should be decided with input from consumers

- **Intended role of the consumer team member:**
 - ✓ As *Consultant* providing expert consumer advice to the project
 - ✓ As *Collaborator* working with researchers on some aspect(s) of the project
 - ✓ As *CO-Researcher* helping develop/define/facilitate the research question/project/work throughout the project
 - ✓ As *Communicator* to assist in the dissemination of information at key points throughout the project and/or at the completion of the project to consumers/public (i.e. knowledge translation and exchange (KTE)). (This role must be defined during initial project planning and development stages with consumer participation.)

2. CONSUMER PERSPECTIVE AND EXPERTISE CONTRIBUTES TO THE VIABILITY AND RELEVANCE OF RESEARCH PROJECTS. THE RANGE OF POSSIBLE ACTIVITIES INCLUDES THE FOLLOWING:

- ✓ liaise with consumers, communities and researcher(s)
- ✓ contribute to writing parts of the grant
- ✓ assume some responsibility for KTE
- ✓ attend and contribute to relevant meetings and teleconferences
- ✓ receive email correspondence and respond as required
- ✓ present abstracts/project information
- ✓ assist in establishing the research agenda

3. SPECIAL REQUIREMENTS OF INDIVIDUAL CONSUMER TEAM MEMBERS SHOULD BE DISCUSSED AND APPROVED IN ADVANCE, SUCH AS:

- **Travel considerations and expenses for participation:**
 - ✓ parking, special transport needs, distance from transportation to meeting place, walking surface
 - ✓ wheel chair accessible – if required
 - ✓ elevator – if required
 - ✓ special meals – if required
- **Teleconference and administrative expenses:**
 - ✓ Teleconference arrangements
 - ✓ Travel arrangements (eg. train, air or disability transport) consumer should be reimbursed
 - ✓ Other – as required
- **Consumer employment considerations:**
 - ✓ time constraints by employer
 - ✓ information for employer
 - ✓ possible reimbursement of lost wages
- **Consumer as caregiver:**
 - ✓ baby-sitting or payment for sitter – as required
 - ✓ other – as required
- **Special consumer knowledge requirements:**
 - ✓ mentoring by research team members and/or knowledgeable consumer(s)
 - ✓ sponsorship to workshops, conferences and symposia
 - ✓ training on scientific terminology, methodology, peer review, statistics, KTE, other as required or beneficial to research project

- **Special health accommodation:**
 - ✓ disease fluctuations and flares may make participation difficult from time to time
 - ✓ rest periods – as required
 - ✓ personal helper - as required

4. EXAMPLES OF HOW CONSUMERS CAN CONTRIBUTE TO A RESEARCH PROJECT:

- **Planning and design:**
 - ✓ project planning or in special area
- **KTE:**
 - ✓ help determine target audiences
 - ✓ help determine when information is to be released
 - ✓ coordinate with consumer organizations (e.g. CAC, CAPA, ACE, ARC)
 - help obtain letters of support for project from patient organizations
 - help recruit subjects/other consumers for project
 - participate in the management/Steering Committee of research project
 - assist with consent process and form development (CAN requires research collaborators to write a letter consenting to participate and to participate in a research project).
 - help design and develop consent form for consumer involvement (see attached sample letter of agreement for comment)
 - assist in writing the consent form
 - help consumers involved become familiar with requirements for consent
 - help consumers involved learn requirements for letter of agreement to participate in the research project.
 - assist with determination of possible conflict of interest
 - assist with determination of ability and knowledge to handle confidential information.

Guideline developed from *The Role of Consumers in Research and the Expectations and Responsibilities of Researchers*, by Anne Dooley. Visit www.arthritisnetwork.ca to read the paper.

**MEMORANDUM OF UNDERSTANDING BETWEEN CAN RESEARCHERS
AND CONSUMERS**

Name and contact information of Principal Investigator and/or Trainee:

Consumer name and contact information:

Name of Project:

Location of the research:

Terms of Reference¹ outlined for the consumer:

Consumer time requirements:

Consumer limitations:

Special Requirements:

Travel considerations and expenses for participation:

Teleconference and administrative expenses:

Consumer employment considerations:

Principal Investigator and/or Trainee Signature

Consumer Signature

¹ Attach Plain Language Summary