



## GUIDE FOR RESEARCHERS AND CONSUMERS

## CONSUMER INVOLVEMENT IN RESEARCH PROJECTS

**Produced by the Consumer Advisory Council  
of the Canadian Arthritis Network**

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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 requiring no reimbursement to consumer
  - ✓ Travel arrangements (eg. train, air or disability transport) should not require reimbursement to consumer
  - ✓ 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.

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Guideline developed from *The Role of Consumers in Research and the Expectations and Responsibilities of Researchers*, by Anne Dooley. Visit [www.arthritisnetwork.ca](http://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 Reference<sup>1</sup> outlined for the consumer:

Consumer time requirements:

Consumer limitations:

Special Requirements:

Travel considerations and expenses for participation:

Teleconference and administrative expenses:

Consumer employment considerations:

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**Principal Investigator and/or Trainee Signature**

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**Consumer Signature**

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<sup>1</sup> Attach Plain Language Summary