



OUR VISION A WORLD FREE OF ARTHRITIS

CANADIAN ARTHRITIS NETWORK | LE RÉSEAU CANADIEN DE L'ARTHRITE

CAPA Canadian Arthritis Patient Alliance
experience · perspective · voice

Consumer Involvement in Research: Lessons Learned from the Canadian Arthritis Network



A Joint Project with the Canadian Arthritis Patient Alliance





Presentation Overview:

- ✓ Consumer Involvement at CAN
- ✓ Why Include Consumers in the Research Process?
- ✓ Why Get Involved?
- ✓ A Brief Overview of the Grant Review Process
- ✓ Do's and Don'ts of Getting Involved in Grant Reviewing





History of CAN (1998-2012)

- Created as a Networks of Centres of Excellence (NCE), part of Canada's flagship research and technology program
- Focused on research and training to improve the lives of people living with arthritis
- Developed a unique research model of multi-disciplinary, multi-sectoral research partnerships





History of CAN (1998-2012)

- Research aimed at: 1) causes of arthritis; 2) treatments and therapies; 3) better understanding the impact and burden of arthritis in everyday life
- Funded more than 200 research projects with more than 1,100 collaborators and partners from Canada and internationally

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





Consumers' Involvement with CAN

- CAN created a unique partnership between researchers and people living with arthritis (i.e. consumers)
- The Consumer Advisory Council (CAC) was comprised of people living with arthritis from across Canada





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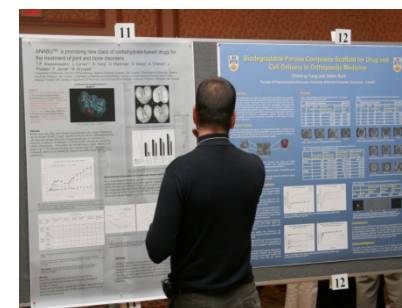
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Consumers' Involvement with CAN

Consumers:

- Helped identify research priorities
- Participated as collaborators in research projects
- Raised awareness and helped disseminate research findings
- Played an active role as peer reviewers for research & training grants
- Participated in CAN governance



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Why Include Consumers in the Research Process?

Because we matter...

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



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Why Include Consumers in the Research Process?

We have insights, experiences, and knowledge of living daily with arthritis that researchers, industry, government, and not-for-profit groups value.



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What are the Benefits for Consumers?

Consumers gain by opportunities to:

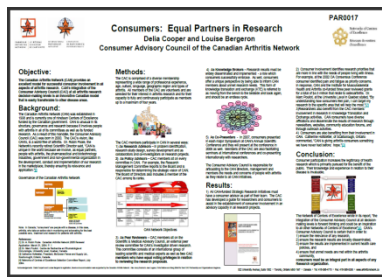
- Help shape and direct research in ways that matter
- Build a network that will advocate for change to improve the lives of people with arthritis
- Help shape the next generation of researchers through involvement in training
- Provide a perspective about living daily with arthritis





Consumer Advisory Council Activities

- Organized and facilitated CAN CARES public forums
- Created a glossary of research terms and *Guide for Researchers and Consumers: Consumer Involvement in Research Projects*
- Participated in strategic planning, conferences and workshops
- Acted as peer-reviewers for research and training grants





Reviewing Grants as a Consumer

Common Types of Grants:

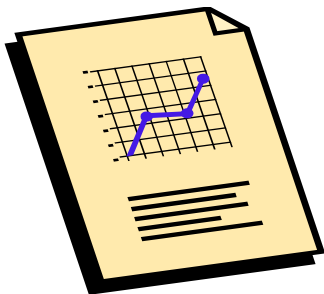
- **Training and New Investigator Grants**

e.g., Masters, PhD, Post Doctoral and Young Investigator grants

Provide salary and research support for students and those early in their career

- **Research Grants**

Provide funding for research projects aimed at a specific topic





Reviewing Grants as a Consumer

Parts of a Grant:

- **Plain Language Summary** - “Your Grandmother should be able to understand why this research matters.”
- **Scientific Summary** - A more detailed summary of the background, methods, and potential impact of the research
- **Research Project Details** - An overview of the project outlining the research gap to be addressed, objectives, research hypotheses (if applicable), methods, research team, and timeline of the study

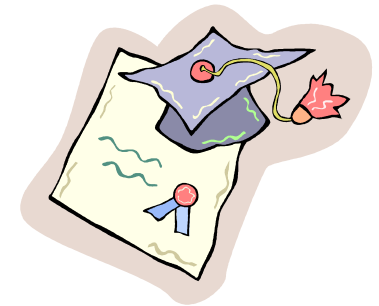




Reviewing Grants as a Consumer

Parts of a Grant:

- **Research Budget** – A detailed list of all expenditures, including salaries, services, supplies, travel, and dissemination costs
- **Curriculum Vitae (CV)** - A summary of all the applicants' education, experience and skills





Reviewing Grants as a Consumer

The Grant Review Process

- The grant review process can differ depending on the funding organization.
- Common elements include:
 - ❑ **A Letter of Intent** – A brief proposal is submitted; those that are ranked highest go forward with a full proposal.
 - ❑ **Reviewing of applications** - A set of criteria are used by each reviewer separately to evaluate and rank grants. Scores may be given to grant components or a total score provided.
 - ❑ **Grant Panel Discussions** – A face-to-face meeting, teleconference, or electronic meeting to discuss grant evaluations and vote on funding of a sub-set of proposals that are highly evaluated.





Reviewing Grants as a Consumer

Questions to think about when reviewing grant applications:



1. Are the research questions and objectives clear?
2. Is there a clear description of the research plan and how it will be carried out?
3. Is the study feasible? Can it be conducted within the budget and timelines of the study? Is this the right team for the job?
4. Do the applicants address potential limitations?
5. Is the research relevant to people with arthritis? Will the results fill gaps in our current knowledge or lead to better new discoveries, treatments, practices or policies?
6. Is there a knowledge translation and dissemination plan?
7. Are consumer collaborators involved? Is their role meaningful?





Reviewing Grants as a Consumer

Expectations Others Have for Consumers:

- To provide written feedback prior to the grant review meeting or teleconference
- To provide verbal feedback during the meeting or teleconference and to vote with other reviewers
- To travel to face-to-face grant review meetings (Note: travel, hotel, and food costs should be covered by the granting agency. Travel cost guidelines must be adhered to)
- To set aside enough time for all aspects of the review process – this is not easy; grant reviewing takes time!





Reviewing Grants as a Consumer

Tips for Talking with the Scientific Experts

- It can be intimidating to share your views on a grant! You're not alone. Researchers feel the same way.
- Reviewers who listen and are respectful are the norm – others will value your expertise.
- Reviewing a grant is a complex process. It is not uncommon for grant scores and evaluations to change when all of the experts have a chance to provide different viewpoints. This is an important part of the process – don't let it stop you from voicing your perspective.
- This will get easier with more experience... Really!





Do's and Don'ts of Getting Involved in Grant Reviewing:

Consumers need to consider whether grant reviewing is right for them. Before agreeing, ask yourself:

1. What is the workload? Is my share of the responsibility excessive?
2. Do I matter? Will I have a mentor? Will I have a vote?
3. Will I receive grant proposals in sufficient time for a thorough review given the other demands in my life?
4. Can I meet the deadlines and accommodate meeting times?
5. Will a plain language summary of the research proposal be provided to help me with the review?
6. Do I have a conflict of interest that I need to declare before I begin reviewing any grants? (e.g., I have worked closely with someone whose grant I am reviewing; I have a personal relationship or have been paid by someone/an organization on the grant application)





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Canadian Arthritis Patient Alliance

The Canadian Arthritis Patient Alliance (CAPA) is a patient-driven organization dedicated to promoting consumer involvement in all aspects of research activities, including grant review.

For more information about CAPA, email us at :

contact@arthritispatient.ca



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Additional Information

Consumer Groups:

- [Arthritis Consumer Experts \(ACE\)](#)
- [Arthritis Patient Advisory Board \(APAB\)](#)
[Arthritis Research Centre of Canada](#)

Resources:

- [The Canadian Arthritis Network](#)
- [The Arthritis Society – Arthritis Research](#)
- [The Arthritis Alliance of Canada](#)





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We are all united by our determination to improve the quality of life for all Canadians with arthritis.

Thank you!



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