



Smart Consumer Partnerships

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September 24, 2003



*Working with The Arthritis Society to make
a difference in the lives of people with arthritis.* 



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What is CAPA?

- **National voluntary organization established in 2001**
- **Self-governing entity of and for Canadians with arthritis**
- **Mission: link Canadians with arthritis for more effective advocacy and improved quality of life for people living with arthritis**
- **Principal partner: The Arthritis Society, which provides material and staff support**
- **Location: www.arthritis.ca/capa**

Types of Participation – which leads to best results ?

- **Co-opted** – tokenism: representatives are chosen, but have no real input or power
- **Co-operating** – tasks are assigned but one group or organization decides the agenda and directs the process
- **Consulted** – opinions are asked but the lead organization decides on the course of action
- **Collaborating** – individuals and organizations work together on the course of action

Why involve Consumers?

Regulators and consumers are – or should be – natural allies.

- Public health and safety are their primary concerns.

- Both want to keep health costs down.

Consumer input is value added

- Consumers can provide input that is timely and appropriate to management needs.
- Consumer perspectives can offer valuable insights into complex issues.
- Direct consumer participation in some programs can increase HPFB efficiency and results.

Why involve Consumers?

Mounting evidence ^{1,2,3,} that consumer involvement in medical research decision making is essential to:

- **Asking meaningful questions**
- **Designing research project protocols**
- **Interpreting project outcomes**
- **Monitoring research progress**

1. [1] Ard, CF, Natowicz, MR. A Seat at the Table: Membership in Federal Advisory Committees Evaluating Public Policy in Genetics. *Am J Public Health*. 2001;91:787-790.
2. [1] Medical research needs lay involvement [editorial]. *Journal of Medical Ethics* 1998;24:291-292.
3. [1] Lay perspectives: advantages for health research [education and debate]. *BMJ* 1998;316:463-466.

Source: C. Koehn, A. Dooley, C. Hofstetter, A. Qualman, *Determining the Research Priorities of People Living with Arthritis: Listening to Patients*, November 2002

When to involve Consumers

- When Regulations deal with more than safety or other technical issues:
 - To reflect **Canadian values**
 - To protect the **public's right to decide**
 - To **override outside pressures** and give priority to health outcomes
- When safety, political or economic risks are high

Which Consumers?

- HPFB should choose consumers according to your needs –
 - a) Individuals who are (practical, honest, assertive, cooperative, analytical, etc.)
 - b) Individuals with **specific skills** and **consumer experience**
 - c) Consumers with strong **networks**

For Smart Consumer Partnerships

- Avoid tokenism: consumer should represent at least 10% - 20% of participants in a multi-sector consultation.
- Have an orientation session for consumers prior to the event: to meet each other and learn about the issues and terminology.
- Revisit confidentiality and other barriers to consumer involvement.
- Commit resources to support consumer participation and consumer education.

Smart Partnerships: New Roles for HPFB & Consumers

- **Greater consumer involvement** in consultations and direct participation in
 - policy development,
 - monitoring
- **Greater HPFB involvement** in support of
 - consumer organizations
 - consumer and public education

Smart Partnerships between Regulators and Consumers...

- are collaborative rather than cynical or confrontational;
- help ensure that regulations are realistic and responsive to patient needs and public preferences;
- help regulators be more efficient and effective guardians of health.

Smart Partnerships between Regulators and Consumers

«It's all about building and
maintaining relationships.»