

# Consumer-driven health care: Building partnerships in research

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## Abstract

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Over the past four decades, there has been a widespread movement to increase the involvement of patients and the public in health care. Strategies to effectively foster consumer participation are occurring within all research activities from research priority setting to utilization. One of the ten principles of the Cochrane Collaboration is to 'enable wide participation', and this includes consumers. The Cochrane Musculoskeletal Group (CMSG) is a review group of 50 within the Collaboration that has been working to increase consumer participation since its inception in 1993. Based in Canada, the CMSG has embraced the concept of knowledge translation as advocated by the Canadian Institutes of Health Research. The emphasis in knowledge translation is on interactions or partnerships between researchers and users to facilitate the use of relevant research in decision making. While the CMSG recognizes the importance of reaching all users, much of its work has focused on developing relationships with people with musculoskeletal diseases to enhance consumer participation in research. The CMSG has built a network of consumer members who guide research priorities, peer review systematic reviews and also promote and facilitate consumer-appropriate knowledge dissemination. Consumers were recruited through links with other arthritis organizations and the recruitment continues. Specific roles were established for the consumer team and responsibilities of the CMSG staff developed. The continuing development of a diversified team of consumer participants enables the CMSG to produce and promote access to high quality relevant systematic reviews and summaries of those reviews to the consumer.

## Background

Over the past four decades, there has been a widespread movement to increase the involvement of patients and the public in health care. As

early as 1978, there was global promotion of this movement by the World Health Organization (WHO), which was evident in the announcement of their vision in primary health: 'The people have the right and duty to participate individually and

collectively in the planning and implementation of their health care'.<sup>1</sup> This vision was soon followed by a strategy for action with the launch of the WHO 'Health for All' strategy. The strategy was based on three principles, one of which was community participation. By the turn of the century, international health agencies were analysing community participation in primary health-care programmes and developing effective methods to promote involvement.<sup>2</sup> Consumer movements in health, often accompanied by legislative support, are now features of the international health scene.

Currently, strategies to effectively foster consumer participation are being developed in all stages of research from research priority setting to utilization. A recent Health Technology Assessment (HTA) Report found over 80 specific efforts to include consumers in identifying and prioritizing health research topics.<sup>3</sup> In the UK, the HTA programme integrates public perspectives by including members of the public on advisory panels to inform, prioritize and refine research topics and to peer review research proposals. The HTA equivalent in Canada, the Canadian Coordinating Office for Health Technology Assessment (CCOHTA), instead focuses on developing consumer involvement in decision-making committees.<sup>4</sup> In primary research, the Consumers' Health Forum of Australia<sup>5</sup> is dedicated to involving consumers in research projects. Similarly, the INVOLVE group, a national advisory group in the United Kingdom promotes consumer involvement in NHS, public health and social care research. Unique to INVOLVE is an additional emphasis to include consumers in communication and research.<sup>6</sup>

The Cochrane Collaboration, an international non-profit organization, also strives to include consumers in the work of their organization. Over 50 groups of the Cochrane Collaboration located across the world produce and promote systematic reviews of health-care interventions. One of the 10 principles of the Cochrane Collaboration is to 'enable wide participation', and this includes consumers (Box 1).<sup>7</sup>

As the Collaboration recognized early that consumers should be active players in the review

**Box 1** Since 1992, The Cochrane Collaboration has evolved rapidly, but its basic objectives and principles have remained constant

The Cochrane Collaboration is an international non-profit organization. It facilitates well-informed decisions about health care by preparing, maintaining and promoting the accessibility of systematic reviews on the effects of healthcare interventions.

The 10 Principles of the Cochrane Collaboration are

- collaboration
- building on the enthusiasm of individuals
- avoiding duplication
- minimizing bias
- keeping up to date
- striving for relevance
- promoting access
- ensuring quality
- continuity
- enabling wide participation

process and uptake, the Cochrane Consumer Network was created to increase worldwide consumer participation. In addition, many of the review groups in the Collaboration are independently endeavouring to include consumers in their work.

The Cochrane Musculoskeletal Group (CMSG) is a review group that has been working to increase consumer participation since its inception in 1993 (Box 2). Members of the CMSG review the literature to determine the best evidence for the interventions of musculoskeletal and arthritic diseases such as rheumatoid arthritis, osteoarthritis, ankylosing spondylitis and gout. Based in Canada, the CMSG has embraced the concept of knowledge translation as advocated by the Canadian Institutes of Health Research (CIHR). CIHR defines knowledge translation as

...the exchange, synthesis and ethically-sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.<sup>8</sup>

The emphasis is on interactions or partnerships between researchers and users to facilitate the use of relevant research in decision making.

**Box 2** The Cochrane Musculoskeletal Group

The Cochrane Musculoskeletal Group (MSG) prepares, maintains and promotes systematic reviews of health-care interventions for musculoskeletal diseases. Based in Canada, it has international acclaim and membership as well as a broad distribution of its editorial. It currently has 269 members: 17 active consumers and members from 26 different countries including eight developing countries.

CIHR defines users as researchers, health-care providers, policy makers, managers, industries and consumers. While the MSG recognizes the importance of reaching all users, much of our work is focused on developing relationships with people with musculoskeletal diseases to enhance consumer participation in research.

Despite a dearth of rigorous evaluations of the benefits of consumer participation, there appears to be a general consensus about potential benefits. Benefits include creating an involved community that is better informed and recognizes the value of research and the research process; allowing consumers to influence research questions and priorities for more relevant research; increasing the accountability of researchers and funding institutions; creating opportunities for consumers to ensure research results are communicated to the community in a usable format; and ensuring that the research is used and applied in health care.<sup>5,6</sup> To achieve these benefits, the MSG has dedicated resources for involving the consumers in all stages of the review process, from setting priorities for review topics to synthesizing the best evidence in systematic reviews. Consumers are also involved in transferring knowledge to people making health-care decisions and in promoting uptake of the results of reviews.

### **Building a network of consumers**

The first step in involving consumers was to recruit health consumers. In the Cochrane Collaboration, the term 'health consumer' applies to anyone who uses, is affected by or is entitled or compelled to use a health-related service. A health consumer is anyone who is

concerned with making wise health-care decisions, whether he or she is a patient, family member or caregiver.<sup>9</sup> It was felt by the Group that people with a musculoskeletal disease would be able to provide the content expertise and the most relevant patient perspective to the musculoskeletal reviews of the MSG. Therefore, to obtain suggestions from active consumers who might be interested in participating, the MSG approached the Canadian Cochrane Centre, the Cochrane Consumer Network, patient groups with similar interests (such as The Arthritis Society of Canada), health charities and other relevant societies. One of our key links was with members of the Arthritis Society, who had already built their own network of consumers interested in research and advocacy.

While most of our consumer members have musculoskeletal diseases and are active in other arthritis groups, they come from a variety of backgrounds and experiences. They include retired health-care professionals, writers and policy consultants. Most members are also based in Canada although international representation is advocated within Cochrane. Despite the fact that most correspondence between the MSG and its consumer members is electronic, it has been easier maintaining and developing relationships with members in the same country as the editorial base. This national emphasis is likely the result of the cohesiveness of the arthritis community in Canada. There are many opportunities for face to face meetings and relationship building through strong arthritis initiatives. These initiatives are supported by the Institute of Musculoskeletal Health and Arthritis as well as the Canadian Arthritis Network. A future challenge for the Group is to increase the involvement of international consumers, possibly through contact with arthritis associations in other countries and the Cochrane Consumer Network.

It has also been a challenge maintaining consumer membership. Consumer members' interests change, time and work commitments fluctuate, and the disease itself affects participation. Members can also participate as

volunteers, working with the CMSG in their 'spare' time. Without direct compensation for the hours and work provided by the members, who often have full-time work commitments, they may not be able to devote consistent time and work to the Group. To overcome barriers, the CMSG is trying to recruit a large consumer membership. The CMSG also tries to ensure that our members do not incur the costs to themselves while participating in or attending Cochrane events (for teleconference calls, parking, etc.). The Group has also appointed a Consumer Group Co-coordinator (a consumer), who is closely connected with the arthritis patient community and is actively recruiting new members for the CMSG.

### Roles of consumer members

With the advice and under the direction of the consumers, a clear (but continually evolving) set of roles for consumers was established early in the partnership. Armed with the background information about Cochrane and discussions over teleconferences, the group worked with the consumers to clearly define their areas of contribution. Recently, a number of initiatives were launched to try and define the roles of consumers with the Cochrane Collaboration. These initiatives, including Horey's<sup>10</sup> survey of consumers and discussion paper of Wale<sup>11</sup>, have provided valuable insight into the development of new roles for our consumer members.

The benefits of consumer participation to the CMSG are evident in the specific activities of our consumer members (Table 1). In general, CMSG consumers provide their expertise in setting research priorities, producing systematic reviews and promoting awareness and use of CMSG reviews. Our topics for priority review have recently changed after surveying our consumer members and their affiliate organizations. Many CMSG systematic reviews focus on drug treatments, whereas the results of the survey clearly indicated that consumers want more information about complementary and alternative treatment options that they can imple-

ment themselves. The Group now encourages new review authors to consider reviewing this literature and current authors to keep these reviews up to date. Consumers also identified the need for more drug to drug comparisons, as most systematic reviews focused on drug to placebo comparisons. As peer reviewers, consumers provide valuable feedback on the clarity of the review, the outcomes and the need for further research. Many consumers have helped to identify research gaps, which review authors include in the 'Implications for Research' sections of CMSG reviews. Concerns about generalizability are often raised by consumers and are again addressed by review authors in revisions.

When peer reviewing, consumers are also asked 'what points do you think are the most important to tell a consumer about this review?' Responses are fed directly into the content for consumer synopses and summaries of the CMSG reviews. In addition, our consumers have been an integral part in the development of the format of our consumer summaries. Consumer summaries of CMSG reviews have been continually developed and written over the past 10 years with the help of our consumer members. There has been an ongoing commitment of the Group and the consumers to provide health information from our reviews in a consumer-friendly format. Today, our consumer summaries are presented in a question and answer format as opposed to a scientific format, which was more difficult to follow. Consultation with the consumer group also strengthened the theory that consumers need different amounts of information to make health-care decisions. For this reason each review is written as a short consumer summary, long summary and decision aid. These consumer summaries are posted on the Arthritis Society of Canada web site (<http://www.arthritis.ca>) and advertised in other Arthritis Society and Canadian Arthritis Patient Alliance communications. This wide dissemination of consumer-friendly information would not have been possible without the links developed with other arthritis consumer organizations that our consumers have helped to build.

**Table 1** Role of consumers in the Cochrane Musculoskeletal Group (CMSG)

Roles for CMSG consumers	Activities
<b>Setting research priorities</b>	
Canvas consumers for research priorities	The CMSG scope and topic list and a priority survey were sent to all consumers from the consumer member's relevant organizations for their input. The scope, topics and priority areas for reviews were modified.
<b>Production of systematic reviews</b>	
Assist with editing of systematic reviews	Every protocol and review receives comments from three peer reviewers including one consumer. The consumer group worked with the CMSG to develop a critical appraisal form for peer reviewing systematic reviews that address consumer issues. Two consumers are also members of the CMSG editorial board
Writing systematic reviews	To date, consumers have shown an interest to be part of a team writing a systematic review
<b>Promoting awareness and use of CMSG reviews</b>	
Raise awareness of the CMSG	Partnerships were made with musculoskeletal organizations and initiatives OMERACT (Outcome Measures in Rheumatoid Arthritis Clinical Trials, <a href="http://www.omeract.org">http://www.omeract.org</a> ) CAPA (Canadian Arthritis Patient Alliance, <a href="http://www.arthritis.ca/resources/advocates/capa/">http://www.arthritis.ca/resources/advocates/capa/</a> ) TAS (The Arthritis Society of Canada, <a href="http://www.arthritis.ca">http://www.arthritis.ca</a> ) Bone and Joint Decade ( <a href="http://www.boneandjointdecade.org">http://www.boneandjointdecade.org</a> ) PANLAR (Pan American League Against Rheumatism, <a href="http://www.panlar.org">http://www.panlar.org</a> ) EULAR (European League Against Rheumatism, <a href="http://www.eular.org">http://www.eular.org</a> ) Patient Partners ( <a href="http://www.arthritis.ca/programs_and_resources/patientpartners/">http://www.arthritis.ca/programs_and_resources/patientpartners/</a> )
Participate in national and international conferences	Consumer members attend and advocate at conferences for Cochrane Collaboration American College of Rheumatology CAPA (Canadian Arthritis Patient Alliance) IMHA (Institute of Musculoskeletal Health and Arthritis)
Recruit new consumers to the group	12 new consumers were recruited by consumer members in the past 2 years
Translate CMSG systematic reviews into consumer-friendly formats	
Assist in the development of consumer-friendly formats of CMSG reviews	Consumer members have been influential in working with the knowledge translation specialist to develop a template for consumer summaries based on the amount of detailed information consumers want
Write and edit consumer summaries	Consumer members have written or edited consumer summaries of CMSG reviews. To date 50% of the CMSG reviews have been produced as consumer-friendly summaries in English and French and are available at <a href="http://www.arthritis.ca/look_at_research/cochrane_reviews">http://www.arthritis.ca/look at research/cochrane reviews</a>
Publish consumer-friendly research results for newsletters	With the help of consumer members, consumer-friendly results have been regularly published in newsletters of arthritis consumer organizations, e.g. The Arthritis Society of Canada print and electronic newsletters and the CAPA newsletter

**Table 1** (Continued)

Roles for CMSG consumers	Activities
Provide input into research for consumer-related knowledge translation	Consumer members were participants, presented and helped to develop knowledge translation initiatives Institute of Musculoskeletal HA Health workshop on Knowledge Translation Defining an effective consumer, CIHR funded grant (CIHR funded grant 2002) Patient partners workshops
Assist with seeking funds	Consumer members have been part of the team of two CIHR-funded grants in 2001 and 2002 and advocate at national levels in Canada for the Cochrane Collaboration and the National Network of Libraries of Health in Canada

### Responsibilities of the CMSG

Consumer participation is not a one way street – the CMSG has learnt from experience that the Group has responsibilities to maintain consumer involvement. It is essential to support consumers by providing training, frequent communication and acknowledgement of their contributions (Table 2). Meeting these responsibilities has resulted in greater consumer participation and

engagement. Our members have personally communicated that they feel part of the team and are also personally benefiting from the experience. Many report that peer reviewing is an excellent opportunity to keep abreast of the current evidence about treatments that affect them individually and collectively. They also like seeing concrete products of their involvement and participation in the group; published reviews and consumer summaries are much more

**Table 2** CMSG's responsibilities to the consumer members

Responsibility	Methods
Provide support: Respond to the needs of members as participants and peer reviewers and provide support to help the consumer group with its tasks	Consumer convener appointed (CMSG staff member) Consumer liaison/co-ordinator appointed (consumer volunteer)
Provide clear expectations: Design-specific terms of reference that describe possible roles for the consumer	Development of roles with consumer input
Communicate: Listen and provide feedback. Give consumers reports about how their advice has been used and acknowledge the consumer contribution	Regular newsletter includes descriptions of consumer activities; consumers are acknowledged in CMSG presentations Consumers evaluate performance and process at least once annually The coordinating editor and editors attend one or more organized consumer group meetings and discuss roles Thank individuals for specific and ongoing contributions
Provide training: Respond to the needs of consumer members for continuing education in research, systematic reviews and the Cochrane Collaboration	One-on-one training Distribution of educational materials Provide funding or avenues for funding to participate in continuing education opportunities Encourage and provide some funding for participation in annual Cochrane Colloquium Provide learning workshops

tangible and immediate than some of the results of their advocacy work to change health care and policy. By providing positive feedback about their participation, our members have described that they have a sense of fulfilment and satisfaction from the work they do for the Group.

Providing training is one of the key responsibilities of the Group that also benefits our consumer members. Training is not only in the systematic review process but also in evidence-based health care. Our consumers have been able to use these skills when advocating for arthritis in general and when participating in other scientific committees. As most of the CMSG consumers have the disease background and patient perspective, training from the CMSG has focused on increasing the scientific background of the members and task training. Therefore, training has focused on the skills needed to perform their primary tasks. These tasks include refereeing reviews, making information available in a consumer appropriate format and informing research priorities. Training starts with one-on-one coaching by providing background material on the systematic review process, as well as running consumer workshops ranging from basic research orientations to appraisal techniques and understanding statistics. Continuing education is also provided through Annual Cochrane Colloquiums and Canadian Cochrane Centre Symposiums. At the 2004 Cochrane Colloquium in Ottawa, the CMSG presented and conducted workshops on evidence-based health and informed decision making, writing consumer summaries and understanding statistics in Cochrane reviews. The conferences provide excellent opportunities to overcome the challenges of training by e-mail, as well as opportunities to acknowledge consumer members and maintain relationships and contacts.

## Conclusion

Researchers and consumers have the opportunity for a mutually beneficial sharing of knowledge.<sup>12</sup> In choosing a more participatory path to knowledge, researchers can benefit from

wider expertise, and be reminded constantly to put people and their needs first.<sup>13</sup> But public participation in health care and its benefits cannot be achieved without the direct involvement of the consumer voice and influence. The effectiveness of that involvement is determined by the characteristics of both the consumer members and the work environment.<sup>12</sup>

Consumer involvement in the CMSG builds on the co-operative spirit that exists within the Cochrane Collaboration. In the CMSG, staff members and the consumer members realized early that they needed to work together to determine and fulfil mutually beneficial roles and goals. The roles of consumers in the CMSG are focused on three main areas to ensure more relevant research: setting priorities, peer reviewing and translating the results of systematic reviews. By involving consumers in setting the research priorities, the CMSG is more confident that their reviews are timely and relevant to the consumers. Furthermore, by involving consumers in the peer review process it is more likely that CMSG reviews answer the questions consumers have about health-care interventions for musculoskeletal diseases. With the assistance of the consumer members, the CMSG is actively ensuring that the information from their systematic reviews is reaching the consumers. The CMSG is also ensuring that this information is in a usable format so that it can be used in evidence-based decision making. It is clear to the CMSG that the enthusiasm and involvement of the consumer group is beneficial and will positively affect health care. It is hoped that our example of consumer participation will continue to inspire new consumer-driven initiatives. Partnership with consumers in research, as in healthcare, is essential.

## References

- 1 World Health Organization. *Declaration of Alma Ata: Report of the International Conference on Primary Health Care*. Geneva: WHO, 1978.
- 2 Bichmann W, Rifkin SB, Shrestha M. Towards the measurement of community participation. *World Health Forum*, 1989; **10**: 467–472.

- 3 Oliver S, Clarke-Jones L, Rees R *et al.* Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. *Health Technology Assessment*, 2004; **8**: 1–148, III–IV.
- 4 Pivik J, Rode E, Ward C. A consumer involvement model for health technology assessment in Canada. *Health Policy*, 2004; **69**: 253–268.
- 5 Consumer's Health Forum of Australia and National Health & Medical Research Council. *Summary Statement on Consumer and Community Participation in Health and Medical Research*. Australia: NHMRC, 2002. [Accessed 29 May 2005]. Available at: [http://www.health.gov.au/publications/\\_files/r23.pdf](http://www.health.gov.au/publications/_files/r23.pdf).
- 6 INVOLVE. *About Us*. 2005. [cited 2005 May 29]. Available at: [http://www.invo.org.uk/About\\_Us.asp](http://www.invo.org.uk/About_Us.asp).
- 7 The Cochrane Collaboration. *The principles of the Cochrane Collaboration*. 2005. [cited 2005 May 29]. Available at: <http://www.cochrane.org/docs/tenprinciples.htm>.
- 8 Canadian Institutes of Health Research. *Innovation in Action. Knowledge Translation Strategy 2004–2009*. Ottawa: Canadian Institutes for Health Research, 2005. [updated 2005 February 14; cited 2005 May 29]. Available at: <http://www.cihr-irsc.gc.ca/e/26574.html>.
- 9 The Cochrane Collaboration. *Cochrane Collaboration Handbook* (online version). 2004. [cited 2004 April 15]. Available at: <http://www.cochrane.de/cochrane/hbook.htm>.
- 10 Horey D. *Survey of Consumers in the Cochrane Collaboration*. The Cochrane Collaboration, 2003.
- 11 Wale J, Horey D, Gyle G. *Consumer Information for Cochrane Review Groups – A discussion paper*. The Cochrane Collaboration, 2002.
- 12 Bastian H. *The Power of Sharing Knowledge: Consumer participation in the Cochrane Collaboration*. 1994. [cited 2005 May 29]. Available at: <http://www.informedhealthonline.org/item.aspx?tabid=37>.
- 13 Saul JR. *Voltaire's Bastards: The Dictatorship of Reason in the West*. Canada: Penguin Books, 1993.