



A Consumer Viewpoint on Involvement in Clinical Effectiveness Activities

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Childbirth Connection

- established in 1918 as Maternity Center Association
- 91 years of working for maternity care quality improvement & advocating on behalf of childbearing women & families
- long-term national program to promote evidence-based maternity care, 1999-
- mission: improve the quality of maternity care through research, education, advocacy and policy



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Consumer Involvement Experience

- **systematic reviews and evidence reports**
 - Cochrane Pregnancy and Childbirth Group, Consumer Panel
 - Cochrane Pregnancy and Childbirth Group, review co-author
 - Agency for Health Care Research and Quality, feedback during evidence report development process
- **performance measures**
 - National Quality Forum, Consumer Council
 - National Quality Forum, Perinatal Care Steering Committee
 - National Quality Forum, Board of Directors
 - National Quality Forum, comments on draft reports and measure sets
- **multi-stakeholder quality improvement consultation/collaboration**
 - *Transforming Maternity Care* project, Consumers and Advocates Workgroup



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Consumer Involvement Experience

- **guidelines**
 - Guidelines International Network, Patient & Public Involvement Group Steering Committee
- **consumer organizations**
 - Consumers United for Evidence-based Healthcare (CUE), Steering Committee
 - Raising Women's Voices, Advisory Board
- **other health care quality organizations**
 - National Committee for Quality Assurance, Consumer Advisory Council
 - Center for Medical Technology Policy, Patient and Consumer Advisory Committee
 - National Priorities Partnership, Overuse Workgroup



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Consumer Involvement Adds Value to Clinical Effectiveness Activities



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Consumers Identify, Can Help Address Valid Issues that Professionals May Not Identify

Common consumer contributions when refereeing draft Cochrane Pregnancy & Childbirth protocols & reviews

- additional outcomes of interest to consumers, including harms, longer-term effects, psychosocial effects, consumer experiences
- need for more background information about condition or intervention, and to include more rigorous evidence in this section
- need for clearer or more sensitive language
- broader implications for research, including more attention to prevention, less invasive interventions, evaluation of presumed indications
- insights that may be more accessible from afar, e.g., potential effect of unmeasured co-interventions and methodologic limitations of RCTs



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Consumers May be More Engaged and Thorough in the Task than Professionals

Evaluation of Cochrane Pregnancy and Childbirth Group Consumer Panel found that consumers tended to give more attention to detail and identify more areas for improvement than peer referees

Pregnancy and Childbirth Group editor:

“I think I can speak for all [the] editors on this because it’s come up at every single one of our editorial meetings, that the [consumer] input in general is fantastic. It’s the highest quality we get. It’s certainly the most detailed and thoughtful.”

Pregnancy and Childbirth Group review author:

“It was very long when it came.... It took me awhile to get over the heart-sink. I mean it was enormously valuable.”



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Consumers Can Contribute to Scientific Matters

Consumers who are motivated to participate in clinical effectiveness activities often will

- care above the evidence base that is available to support conclusions, recommendations, and policies
- use Pub Med and other sources to follow the literature of interest carefully
- communicate through blogs, list serves, and other means with those who share their interests
- develop critical appraisal skills



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Consumers Can Fill Roles that Health Professionals May Not Assume

- Cochrane review team division of labor: lead author — data analysis and writing, low-income country author — issues relevant to low-income countries, statistician — methods issues, consumer — consumer concerns
- In refining and finalizing various Childbirth Connection projects, feedback from members of National Advisory Council often reflects their disciplinary concerns



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Consumer Involvement Can Broaden Perspectives of Professionals

In view of long-time editor of Cochrane Pregnancy and Childbirth Group, work with Consumer Panel has broadened professional perspectives and sensibilities of the review group members

Pregnancy and Childbirth Group author, in evaluation:

It's important that the Consumer Panel continues to teach us about the importance ... of the patient's view, of adverse effects, and of an accessible language.



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Consumer Involvement Requires a Strategic, Sustained Commitment



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Leadership is Important

Early Cochrane leaders valued, aimed to include consumers in all aspects of Cochrane work, and much of that ethos continues

- Cochrane Steering Group has 2 consumer seats, with staggered terms
- Cochrane Consumer Network, or CCNet, looks after consumer issues across the collaboration
- each review group is expected to engage consumers in carrying out its work
- Pregnancy and Childbirth Review Group values this work enough to include support in their budget almost every year, and to assume the extra administrative work of involving consumers



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Structure, Strong Personnel Can Contribute to Success

Success of Cochrane Pregnancy and Childbirth Group Consumer Panel attributed to ongoing structure and support:

- long-time Principal Consumer Coordinator with personal experience of consumer advocacy, childbirth educator background
 - active in training and recruitment
 - skillful intermediary between professionals and consumers
 - flexibility, e.g., in consumer availability and feedback formats
- comments of editors to evaluator:
 - “I think the summary comments from our consumer coordinator, they are by far the biggest influence.”
 - “It works well because we’ve got a ... dedicated person, that can coordinate and work with consumers, who understands what they are saying, at the same time understands what the review needs.”



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Consumer Training, Ongoing Technical Assistance Enhance Effective Involvement

- Consumer-Purchaser Disclosure Project
 - holds regular webinar briefings for members
 - prepares sign-on letters, fact sheets and other resources
 - advises members on National Quality Forum commenting and voting opportunities
- *Transforming Maternity Care* priority consumer recommendation: create ongoing structure and process for identifying consumer advocates with leadership potential, and provide them with training and ongoing support to participate effectively in clinical effectiveness activities
- Outstanding model: Project Lead of National Breast Cancer Coalition — intensive training for participation on research proposal panels and other scientific bodies



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Systematic Processes are Needed to Understand Consumer Views and Experiences

Example of national *Listening to Mothers* surveys: LTM I, LTM II, & *New Mothers Speak Out* reports — data on childbearing women's:

- experiences, including clinical practices not collected at the national level or known to be undercounted in official statistics
- maternity care quality issues, including evidence-practice gaps
- knowledge and beliefs
- preferences
- full childbearing cycle from before pregnancy through postpartum period

Reports & questionnaires: www.childbirthconnection.org/listeningtomothers



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If Processes are Not Followed Upstream, Consumers May Not Support Downstream

Lessons from performance measurement activities

- NQF Steering Committee voted to support DVT prophylaxis measure for women undergoing cesarean section despite lack of evidence
- Steering Committee deferred decision on bilirubin screening measure until completion of U.S. Preventive Services Task Force report, which concluded not enough evidence to recommend
- A partner of Childbirth Connection evaluated hospitals on their use of DVT prophylaxis with cesarean and bilirubin screening
- Childbirth Connection is unable to join with this group in issuing a press release about these results, as evidence is lacking and this could undermine support for performance measurement



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Longitudinal Engagement May Lead to Greatest Gains from Consumer Involvement

Experience with Agency for Healthcare Research and Quality's Vaginal Birth After Cesarean Evidence Report

- Brief teleconference consultations with Technical Expert Panel: difficult to raise consumer issues and concerns in brief time allotted
- Refereeing of full draft evidence report offered much better opportunity for input and dialogue
- Potential for continued involvement in process: consensus conference to release results and professional and consumer summary guides
- Substantive consumer involvement at all stages of process ideal



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Thank you!

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