Supplementary Online Material

Kreis J, Puhan MA, Schünemann HJ, Dickersin K. Consumer Involvement in Systematic Reviews of Comparative Effectiveness Research. *Health Expectations.*

Appendix S1: Items covered in the interviews

A. Introduction with oral consent

B. Contextual Information

- Interviewee’s role at the organization
- Contextual information about the task of the organization including whether they conduct or commission systematic reviews
- General processes of review conduct or commissioning

C. Involvement of Stakeholders

- Involvement of stakeholders
- Involvement of consumers
- Definition of “consumers”
- Types of consumers involved
- Involvement as representatives vs. as individuals
- Main rationale for involving consumers

D. Consumer involvement in the different stages of conducting systematic reviews

- Involvement in the identification and prioritization of topics
- Involvement in the protocol stage
- Involvement in the review stage
- Involvement in the translation of results into a consumer-friendly language
- Involvement in the dissemination of results
- Involvement in supporting activities (e.g., hand searching)
- Involvement in other aspects

E. Structural aspects of consumer involvement

- Involvement at the organization’s policy level
- Involvement in advisory groups
- Involvement as review authors
- Form of involvement: ad hoc consultation
- Involvement in a consumer network
- Person responsible for consumer involvement
- Number of consumers usually involved in one review
- Number of reviews one consumer is usually involved in

F. Recruitment of consumers

- Establishment of contact to consumers
- Selection of consumers
- Prerequisites for involvement
- Disclosure of potential conflicts of interest
- Types of consumers involved in the assessment of screening programs

G. Training

- Provision of training for consumers
- Development of the training for consumers
- Content of the training for consumers
- Experiences with the training for consumers
- Plans to provide training for consumers in the future
- Provision of training for researchers

H. Compensation

- Compensation of consumers
- Reimbursement of costs that incur
- Acknowledgement of consumers for their input in the review

I. Evaluation of the experience with involving consumers

- Definition of “successful” consumer involvement
- Formal evaluation
- Informal evaluation: personal impression of the impact concerning quality and usefulness of reviews, examples where consumer involvement made a difference
- Secondary benefits
- Potential negative impact and measures against it
- Circumstances where consumer involvement might be less relevant
- Processes that work especially well / not so well
- Facilitators, critical success factors
- Barriers
- Experiences with different types of consumers

J. Reasons for not involving consumers

- Past experiences with consumer involvement
- Main reasons for not involving consumers
- Concerns regarding consumer involvement
- Support needed to implement consumer involvement
- Plans to involve consumers in the future

K. Summing up

- Recommendations concerning consumer involvement in systematic reviews
- Concerns or hopes concerning consumer involvement
- Anything the interviewee would like the IOM to know concerning consumer involvement in systematic reviews

Appendix S2: Complete list of organizations approached in the study

Organizations commissioning systematic reviews (outsourced or in-house)[a]

- Agency for Healthcare Research and Quality (Effective Health Care Program; all outsourced) with the Center for Evidence-based Policy[b]

Professional societies

- American Academy of Pediatrics (in-house/outsourced)
- American College of Chest Physicians (outsourced)

Provider / payer / research organizations

- Centers for Medicare and Medicaid Services (in-house/outsourced)
- Office of Medical Applications of Research, National Institutes of Health (outsourced)
- U.S. Department of Veterans Affairs (outsourced)

Organizations conducting systematic reviews

U.S.-based organizations

- Johns Hopkins Evidence-based Practice Center (EPC)
- Oregon Evidence-based Practice Center (EPC)
- ECRI Institute (non-EPC)[c]
- Blue Cross and Blue Shield Association, Technology Evaluation Center (non-EPC)[c]
- Kaiser Permanente, National Guideline Program[d]
- Hayes, Inc.
- Mayo Clinic, Knowledge and Encounter Research Unit

International organizations and groups

- Campbell Collaboration[e]
- Cochrane Collaboration (Steering Group)[f]
  - Cochrane Musculoskeletal Group
  - Cochrane Pregnancy and Childbirth Group

Organizations approached that reported they neither commission nor conduct systematic reviews

National Institute of Mental Health

American College of Obstetricians and Gynecologists

Organizations that were not available in the time frame of the project

National Cancer Institute

a: outsourced = the conduct of the systematic reviews is usually commissioned to external organizations, in-house = systematic reviews are conducted by people internal to the organization

b: 2 interviews were held – one with key informants of AHRQ, the other one with a key informant of the Stakeholder Engagement Team of the Scientific Resource Center based at CEbP which provides scientific support for AHRQ. To simplify matters, we generally only refer to “AHRQ” in the following tables; however, this includes the activities carried out by the Stakeholder Engagement Team on behalf of AHRQ.

c: Although both institutes serve as EPCs for AHRQ, the interviews focused on the processes for systematic reviews by non-federal commissioners as these are the majority of systematic reviews carried out at these organizations. For those systematic reviews commissioned under the EPC-funding, AHRQ’s processes for consumer involvement apply.

d: At Kaiser Permanente, systematic reviews are also commissioned.

e: The information provided in the interview mainly refers to processes at the former Nordic Campbell Center (SFI Campbell).

f: For the Cochrane Collaboration as a whole, the interview was carried out with a key informant of the Steering Group.

Total organizations: 20

Organizations with in-depth interviews: 17

Number of interviews carried out: 18

Appendix S3: Description of organizations that reported usually involving consumers in systematic reviews

Organization	Description
Agency for Healthcare Research and Quality with the Center for Evidence-based Policy	The Agency for Healthcare Research and Quality commissions systematic reviews to its 14 Evidence-based Practice Centers (EPCs). Several models are implemented to inform various stakeholder needs: Technology Assessments are commissioned for the Centers for Medicare & Medicaid Services, reviews for the U.S. Preventive Services Task Force, Generalist and Comparative Effectiveness Reviews for public audiences, and reports commissioned for Federal Partners. Comparative Effectiveness Reviews are prepared under the Effective Health Care (EHC) Program which was created from the Medicare Prescription Drug, Improvement, and Modernization Act (MMA) in 2003; the first of these reviews was published in 2005. Since its inception, methods of involving the public in this program have been developed. The Stakeholder Engagement Team of the Scientific Resource Center based at the Center for Evidence-based Policy supports the EHC Program in these activities. The translation of the evidence into a consumer-friendly language is carried out by the Eisenberg Center. Website: http://www.ahrq.gov/
Johns Hopkins Evidence-based Practice Center	The Johns Hopkins EPC has been designated by AHRQ in 2002. While projects that are funded within the EPC stream are commissioned by AHRQ, some projects have also been carried out for other organizations, e.g., a professional society. Website: http://www.jhsph.edu/epc
Oregon Evidence-based Practice Center	The Oregon EPC has been preparing systematic reviews since 1997. Commissioners include AHRQ, the Drug Effectiveness Review Project (DERP), the U.S. Preventive Services Task Force or Federal Partners such as the National Institutes of Health or the Centers for Disease Control. Website: http://www.ohsu.edu/epc/
Cochrane Collaboration	The Cochrane Collaboration, established in 1993, is an international network of people preparing, updating and promoting the accessibility of Cochrane Reviews. 52 editorial groups (Review Groups) are responsible for reviews in a particular content area. Some of these groups cover clinical areas while others are much broader. All review authors go through the formal process of one of these groups. This includes a registration and approval of the title, the preparation and peer review of a protocol and the preparation, peer review and approval of the review by the respective editorial group. Review topics are mainly identified based on the interests of the authors and the editorial groups. However, the Cochrane Collaboration is increasingly commissioned for specific reviews or receives grant funding schemes that encourage reviews in certain areas. In the latter case, the funder chooses an area, and the authors and the editorial group determine the specific topics. Commissioners include, for example, the World Health Organization or government organizations. Website: http://www.cochrane.org/
Cochrane Musculoskeletal Group	The Cochrane Musculoskeletal Group is one of 52 Review Groups and produces Cochrane reviews on the prevention, treatment or rehabilitation of musculoskeletal disorders. The main editorial base is located in Canada. Website: http://www.cochranemsk.org/
Cochrane Pregnancy and Childbirth Group	The Pregnancy and Childbirth Group is one of 52 Review Groups in the Cochrane Collaboration and was the first group to be formed. It prepares and maintains Cochrane reviews of interventions that relate to pregnancy and childbirth, and up to 30 days following childbirth, as well as lactation. Website: http://pregnancy.cochrane.org/
Campbell Collaboration (SFI Campbell/former Nordic Campbell Center)	The Campbell Collaboration, founded in 2000, is an international research network that produces systematic reviews of the effects of interventions in the areas of education, crime and justice, and social welfare. Campbell's International Secretariat is located in Oslo and hosted by the Norwegian Knowledge Centre for the Health Services. So far, 58 Campbell reviews have been completed. Campbell reviews are usually not commissioned. Instead, they are carried out by researchers as part of their ongoing academic work. In 2002, the Nordic Campbell Center (today called SFI Campbell) based in Copenhagen, Denmark, was established. The Nordic Campbell Center developed a model for how users should be involved in reviews that are carried out in cooperation with this center and funded all user-related activities. On top of this, the Center made a – typically smaller – amount available directly to the review authors. However, there is no funding for this type of activity available at the

aggregate level of the Campbell Collaboration. The description of processes in this article mainly refers to processes which were in place at the Nordic Campbell Center/SFI Campbell during the last years, before the former director left this position. The views expressed represent the opinion and experience of the interviewee and not the official Campbell Collaboration.

Instead of the term “consumer”, the term “user” is used in the Campbell Collaboration. “Users” are very broadly defined as “everybody who is not a researcher”. The “users” involved at Campbell are different from the consumers involved in the other organizations of our sample: A genuine “end-user” (i.e,. an imprisoned drug addict, a child placed in care, a homeless person, an unemployed person, etc.) is usually not involved, but instead a person from their interest organization. Also, frontline practitioners, knowledge exchange organizations, professional organizations and labor unions are involved as “users”.

Website: http://www.campbellcollaboration.org/; http://www.sfi.dk/Default.aspx?ID=2836

Appendix S4: Approaches for consumer involvement that have been used

Preamble:

The interviews revealed that the approaches for involving consumers differ depending on the commissioner and evolve constantly as they are subject to many ongoing changes, for example because of (loss of) funding, because persons responsible for the activity leave the organization or because of the advancement of methods. The aim of this table can therefore not be to describe what is currently done at each organization, but rather to show the variety of different approaches possible to involve consumers. To this end, all approaches that were reported in the interviews are depicted below, irrespective of whether they are applied regularly or only in exceptional cases or whether they were only applied in the past.

Explanation:

yes = this approach is depicted in Figure 1 or Figure 2 and the according organization is listed as an example for that approach; [yes] = this approach is depicted in Figure 1 or Figure 2, however, a different organization is listed as an example for that approach; no = this approach is not depicted in Figure 1 or Figure 2

Organization	**Approaches for involving consumers in systematic reviews described in the interviews**	**Depicted in Figure 1 or in Figure 2**
AHRQ (EHC Program)	**Topic identification:**	
	• Topic suggestions via EHC Program's website	yes
	• Open-door listening sessions, for example to discuss the priority conditions	no
	Protocol stage:	
	• Key informants for the development of the key questions	[yes]
	• Consumer peer review of that part of the protocol which includes the key questions by the key informants	[yes]
	• Public comment	yes
	AHRQ distinguishes processes for refinement of key questions (PICO) from development of the protocol, which focuses on refinement of the scientific aspects of the protocol. Consumers are heavily involved in refinement of key questions. Technical experts are used more for refinement of the protocol's scientific aspects.	
	Review stage:	
	• Public comment	yes
	Translation & dissemination:	
	• Focus group and cognitive testing with consumers to develop consumer-friendly information material; carried out by the Eisenberg Center	yes
	• Testing of the EHC Program's website which is the main way to disseminate the results	no
	• Targeted outreach activities and other marketing pitches (AHRQ's Office of Communication and Knowledge Transfer)	no
	• Support research on innovative ideas for dissemination with iADAPT grants (Innovative Adaptation and Dissemination of AHRQ Comparative Effectiveness Research Products)	no
	Further forms of involvement:	
	• Stakeholder group	yes
Campbell Collaboration (SFI Campbell/ former Nordic Campbell Center)	**Topic identification:**	
	• Topic suggestions via central Campbell Collaboration website ("Burning Questions")	[yes]
	Protocol stage:	
	• Advisory group meeting: Researchers meet with the advisory group members to discuss the draft protocol[a]	yes[b]
	Review stage:	
	• Advisory group meeting: Researchers meet with the advisory group members to discuss the draft review[a]	yes[b]
	Translation & dissemination:	
	• Advisory group meeting: Researchers meet with the advisory group to write user abstracts[a]	yes[b]
	• Development of templates for user abstracts by the Campbell Collaboration Users	[yes]

	Group	
	• Semi-structured interviews with people in the field or members of the advisory group to prepare “contextualized user abstracts”[a]	no
	• “What Works” conferences with workshops based on a systematic review, where a researcher presents the review results and a best-practice practitioner speaks about his or her experience with the intervention and/or in the advisory group[a]	no
	Further forms of involvement:	
	• Advisory group[a]	yes
	• Policy level – Steering group: The two chairs of the Campbell Users Group are members of the Campbell Collaboration’s Steering Group.	[yes]
	• Consumer network: The so-called “Users Group” is a platform for people from currently about 25-30 organizations who see themselves as non-researchers and want to engage in the organization and who want their viewpoints to be heard at Campbell, for example at the Colloquia or at the Steering Group meetings.	[yes]
Cochrane Collaboration – Steering Committee	**Topic identification:**	
	• Prioritization projects: During the last few years, the Cochrane Collaboration funded a series of prioritization projects, and several of those projects had very different ways of involving consumers in the prioritization of reviews.	no
	Protocol stage:	
	• Interviews with patients (and spouses)	no
	• Consumer peer review of the draft protocol	[yes]
	Review stage:	
	• Co-authorship or lead authorship	[yes]
	• Consumer peer review of the draft review	[yes]
	Translation & dissemination:	
	• Writing of consumer-friendly summaries: Consumers write the first draft or participate in the writing	yes
	• Active dissemination of review results by CCNet through their website and in collaboration with review groups	no
	Further forms of involvement:	
	• Policy level – Steering group: Two positions are held by representatives of the consumer network.	yes
	• Consumer network: CCNet	yes
	• Supporting activities (e.g., hand searching): Consumers are involved as hand searchers. They are usually associated with an individual Review Group, Center or Field.	yes
	• Advisory groups for some reviews	[yes]
Cochrane Musculoskeletal Group	**Topic identification:**	
	• Workshops: Two workshops have been carried out with consumers to identify priorities in musculoskeletal health in brainstorming sessions.	yes
	Protocol stage:	
	• Consumer peer review of the draft protocol	yes
	Review stage:	
	• Co-authors: There have been two exceptions where consumers have been co-authors after they had been involved for a very long time.	[yes]
	• Consumer peer review of the draft review	yes
	Translation & dissemination:	
	• Development of the format of a consumer-friendly summary: Consumers were involved in creating this format and they were consulted in focus groups before the format was tested in the trial.	[yes]
	• Publishing of consumer-friendly summaries: Consumer stakeholders outside of the CMSG consumer network are involved in disseminating in the way that this summary (translated into French and English) is sent to the Arthritis Society in Canada, which publishes it on its website and updates it on a regular basis.	no

	• Recruitment of new consumers: Members of the CMSG consumer network recruit other consumers.	no
	• Posters and presentations: Members of the CMSG consumer network have posters or oral presentations together with the Knowledge Translation Specialist, for example at the Canadian Cochrane Symposium.	no
	Further forms of involvement:	
	• Policy level – Editorial board: The Consumer Editor, a member of the CMSG Consumer Network, sits on the editorial board of the CMSG and as such is part of any editorial decisions.	[yes]
	• Consumer network: The CMSG has its own consumer network of about 30 to 35 consumers of which about 20 are currently actively involved. The main task of the consumers in the network is to carry out review of the draft protocols and draft reviews.	[yes]
Cochrane Pregnancy and Childbirth Group	**Topic identification:**	
	• Consumer involvement at this stage happens only informally, e.g., when consumers give feedback on reviews.	no
	Protocol stage:	
	• Consumer peer review of the draft protocol	[yes]
	Review stage:	
	• Co-authors: Some consumers (primarily consumer advocates) have been co-authors of reviews.	yes
	• Consumer peer review of the draft review	[yes]
	Translation & dissemination:	
	• Comment on consumer-friendly summaries: In some cases, the authors write the consumer-friendly summary and the consumers can comment on this as part of their review.	no
	• Writing of consumer-friendly summaries.	[yes]
	Further forms of involvement:	
	• Consumer Panel: The main task of this panel is to review drafts of protocols, of systematic reviews, and of review updates.	[yes]
Johns Hopkins EPC	**Topic identification:**	
	• The EPC usually receives the commission from AHRQ (or other organizations, see above) and is therefore not directly involved in this stage. For reviews under AHRQ's EHC Program, the public can submit suggestions for topics.	[yes]
	Protocol stage:	
	• Key informants for the development of the key questions	[yes]
	• Public comment	[yes]
	• Advisory group: In individual cases, if there is a consumer-oriented organization on the Technical Expert Panel, they have input at this stage.	[yes]
	Review stage:	
	• Occasionally one of the members of the research team happens to have the condition of interest. Their role is then unique in that they bring a perspective that an external consumer representative would bring, even though they are not necessarily thought of as being consumer representatives.	no
	• Consumer peer review: In addition to the clinical or methodological experts who are on the Technical Expert Panel, a patient representative – usually one per review – is identified who is willing and able to comment on the draft review.	yes
	• Public comment	[yes]
	Translation & dissemination:	
	• For reviews commissioned by AHRQ, the translation of findings is carried out by the Eisenberg Center.	[yes]
Oregon EPC	**Topic identification:**	
	• For reviews under AHRQ's EHCP, the public can submit suggestions for topics.	[yes]

	Protocol stage:	
	• Key informants for the development of the key questions: Interviews are carried out with patients who have the target condition under review and/or relatives and caregivers. In some cases, also focus groups or discussions together with clinicians are carried out.	yes
	• Public comment	[yes]
	Review stage:	
	• Public comment	[yes]
	Translation & dissemination:	
	• The EPC works with the NLM to translate the results of reviews so that they can help answer the public's questions submitted through PubMed.	no

a: These processes were in place at the Nordic Campbell Center/SFI Campbell during the last years.
b: These meetings are not depicted explicitly in Figure 1, but they are part of the ongoing involvement in an advisory group.

Appendix S5: Types of consumers involved in systematic review processes

Organization	Types of consumers involved in systematic review processes	
AHRQ (EHC Program)	Patients with personal experience of the target condition:	yes
	Patients without personal experience of the target condition:	(yes)[a]
	Patient advocates, e.g., members of patient organizations:	yes
	Spouses / families / caregivers:	yes
	Members of the public:	yes
	Consumer representatives:	yes
	Children:	no[b]
	Professionals who work with patients:	yes[c]
	Others:	no
	[a]: Patients without personal experience of the target disease may have been involved, yet patients with more direct experience of the disease addressed in the review are usually preferred.	
	[b]: Children have not yet been involved; however, this is not by design and may be realized in the future.	
	[c]: Professionals from advocacy organizations who work with patients have been involved to represent the consumer perspective.	
Johns Hopkins EPC	Patients with personal experience of the target condition:	yes
	Patients without personal experience of the target condition:	no
	Patient advocates, e.g., members of patient organizations:	yes
	Spouses / families / caregivers:	yes[a]
	Members of the public:	no
	Consumer representatives:	yes
	Children:	no
	Professionals who work with patients:	no[b]
	Others:	no[c]
	[a]: Caregivers or family members may be involved, depending on the topic. For example, in a review project on conditions like Alzheimer's disease or management of geriatric conditions or some serious pediatric illnesses, input from family members may be desired, although they are otherwise usually not specifically involved.	
	[b]: The EPCs include clinicians in the development of the key questions to represent their clinical perspective, rather than to represent the perspective of the patients. However, it was mentioned that it may be difficult to disentangle their view of the patient's perspective from their own perspective as a clinician.	
	[c]: The payer perspective is usually included as an additional perspective.	
Oregon EPC	Patients with personal experience of the target condition:	yes
	Patients without personal experience of any kind of condition:	no
	Patient advocates, e.g., members of patient organizations:	yes[a]
	Spouses / families / caregivers:	yes
	Members of the public:	yes[b]
	Consumer representatives:	partially[c]
	Children:	no
	Professionals who work with patients:	(yes)[d]
	Others:	no
	[a]: The Oregon EPC tries not to exclusively use advocacy organizations.	
	[b]: Members of the public are involved in the way that the draft protocols and draft reviews are publicly posted to elicit public comment.	
	[c]: For example, for DERP reports, volunteers – citizens of Oregon – were involved in contributing to the questions for the review.	
	[d]: Clinicians are involved, but to represent their own perspective, not the patients' perspective.	
Campbell Collaboration (SFI Campbell/former Nordic Campbell	Patients with personal experience of the target condition:	n.a.
	Patients without personal experience of the target condition:	n.a.
	Patient advocates, e.g., members of patient organizations:	n.a.

Center)	Spouses / families / caregivers:	n.a.
	Members of the public:	no
	Consumer representatives:	no
	Children:	no
	Professionals:	yes
	Others:	yes[a]
	[a]: Knowledge exchange organizations, professional organizations, labor unions, (frontline) practitioners, persons from organizations that represent the interest of genuine “end-users” (i.e., an imprisoned drug addict, a child placed in care, a homeless person, an unemployed person, etc.)	
Cochrane Collaboration – Steering Committee	Patients with personal experience of the target condition:	yes
	Patients without personal experience of the target condition:	yes[a]
	Patient advocates, e.g., members of patient organizations:	yes
	Spouses / families / caregivers:	yes
	Members of the public:	no[b]
	Consumer representatives:	yes
	Children:	no
	Professionals who work with patients:	no
	Others:	yes[c]
	[a]: Some groups’ reviews deal with healthcare processes rather than individual diseases, so their consumers have that kind of broad focus as well. [b]: No attempts are made to recruit this group of consumers, but there may be some people who fall into this category. [c]: James Lind Alliance, healthtalkonline.org	
Cochrane Musculoskeletal Group	Patients with personal experience of the target condition:	yes
	Patients without personal experience of the target condition:	(yes)[a]
	Patient advocates, e.g., members of patient organizations:	yes
	Spouses / families / caregivers:	no
	Members of the public:	no
	Consumer representatives:	yes
	Children:	no
	Professionals who work with patients:	no[b]
	Others:	no
	[a]: In general attempts are made to match the consumer to a systematic review that has to do with the disease that they have. In cases where no consumer is available with the specific condition under review, a consumer with a related condition may be involved. However, all consumers involved have experience with some kind of musculoskeletal condition. [b]: Some of the consumers involved happen to have previously been healthcare professionals.	
Cochrane Pregnancy and Childbirth Group	Patients with a personal experience of the target condition:	yes
	Patients without a personal experience of the target condition:	yes[a]
	Patient advocates, e.g., members of patient organizations:	yes
	Spouses / families / caregivers:	no[b]
	Members of the public:	no
	Consumer representatives:	yes[c]
	Children:	no[d]
	Professionals who work with patients:	no[e]
	Others:	no
	[a]: Although it is considered ideal to involve consumers with an experience, for less common conditions or treatments it is sometimes not possible to track people with personal experience. [b]: Families, relatives or spouses are not involved on a regular basis; this may only be the case when the review is specifically about that aspect (e.g., partner involvement). [c]: However, this only refers to consumer organizations relevant to the topic, not general ones. [d]: Children who are affected by the reviews are too young to be involved (newborns). [e]: Professionals in the field of maternity care are usually not involved in representing the	

	consumer perspective, although this may have occurred in rare cases. It is considered to be difficult for those groups of people to really have the consumer perspective as the frame of reference when they work in a system that may have interests that are different from that of consumers.

Appendix S6: Recruitment strategies

Organization	Main strategies for the recruitment of consumers[a]
AHRQ (EHC Program)	The recruitment of consumers varies depending on the stage where the consumer is involved. • Volunteering (for topic nomination) • Maintenance of a database of stakeholder groups (for key informants) • Contacts to patient organizations or experts (for key informants) • Local advertising (for involvement in the translation of results)
Johns Hopkins EPC	• Requests to Consumers United for Evidence-based Health Care for relevant patient organizations • Contacts to patient organizations • Contacts to clinical colleagues
Oregon EPC	• Requests to the Stakeholder Engagement Team of the Scientific Resource Center for relevant patient organizations • Contacts to patient organizations • Contacts to clinical colleagues, local clinics etc.
Campbell Collaboration (SFI Campbell/former Nordic Campbell Center)	• Suggestions by researchers of relevant organizations in the field • Use of prior knowledge about relevant organizations in the field • Searches in the internet and in publications for relevant organizations
Cochrane Collaboration – Steering Committee	• Sending out review requests via CCNet's moderated email list of consumers • Publishing of a newsletter by CCNet Further strategies may be used by the 52 different Review Groups.
Cochrane Musculoskeletal Group	• Contacting consumers in the consumer network (for consumer peer reviewers) • Requests by consumers to get involved: either they approach CCNet or someone in the larger Cochrane Collaboration and their name gets passed on or they answer the call for volunteers on the Group's website (for members of the consumer network) • Active approaches of interested consumers by the consumer coordinator (for members of the consumer network)
Cochrane Pregnancy and Childbirth Group	• Contacting consumers on the consumer panel (for consumer peer reviewers)

a: This list is not exhaustive, but reflects the most important strategies that were reported by the interviewees.

Appendix S7: Financial compensation of consumers

Organization / group	**Financial compensation for the time**	**Reimbursement of costs**
AHRQ and commissioned EPCs (EHC Program)	• *Involved as key informants:* usually not • *Involved as peer reviewers:* yes (consumers who act as peer reviewers receive the same honorarium other peer reviewers would get) • *Involved in the translation of results:* yes	• The rules presiding at the respective IRB are applied.
Campbell Collaboration (SFI Campbell/former Nordic Campbell Center)	• Consumers are not financially compensated for their time.	• Reimbursement of travel costs and hotel expenses in connection with advisory group meetings
Cochrane Collaboration – Steering Committee	• Consumers are not financially compensated for their time.	• Varies across the Review Groups • Stipends for the annual Cochrane Colloquium
Cochrane Musculoskeletal Group	• Consumers are not financially compensated for their time.	• Stipends for trainings
Cochrane Pregnancy and Childbirth Group	• Consumers are not financially compensated for their time.	• Stipends for the annual Cochrane Colloquium

Appendix S8: Handling of potential conflicts of interest of consumers

Organization	Handling of potential conflicts of interest
AHRQ and commissioned EPCs (EHC Program)	• Consumers involved in reviews commissioned by AHRQ have to disclose potential conflicts of interest. • So far this has not resulted in an exclusion from participation.
Campbell Collaboration (SFI Campbell/former Nordic Campbell Center)	• Users involved as stakeholders do not usually have to disclose potential conflicts of interest. • Financial conflicts of interest play a smaller role in the social sciences. Involvement of stakeholders with a strong interest (i.e., an “intellectual” conflict of interest) is encouraged.
Cochrane Collaboration – Steering Committee	• If consumers are authors of a review, potential conflicts of interest have to be disclosed. • For involvement in other processes such as translation of the review results into a consumer-friendly summary, the policy is less clear.
Cochrane Musculoskeletal Group	• There is no process in place concerning the disclosure of potential conflicts of interest of consumers.
Cochrane Pregnancy and Childbirth Group	• There is no process in place concerning the disclosure of potential conflicts of interest of consumers.

Appendix S9: Training provided to consumers or researchers

Organization	Methods training provided to consumers	Training in consumer involvement provided to researchers
AHRQ (EHC Program)	• No formal training is provided to consumer participants. • Some very basic materials have been developed that may be used to inform stakeholders and especially consumers about the research process.	• When AHRQ started using key informants, some informal training for investigators in terms of webinars or conference calls was done to review the processes. • The Stakeholder Engagement Team developed a more formal training for researchers which is aimed at preparing them for involving stakeholders, including consumers.
Johns Hopkins EPC	• No formal training is provided to consumer participants.	• No formal training is provided to researchers, but as the involvement of consumers is a routine part of the process, they learn about it in the course of following the EPC protocol.
Oregon EPC	• No formal training is provided to consumer participants.	• No formal training is provided to researchers.
Campbell Collaboration (SFI Campbell/ former Nordic Campbell Center)	• The co-chair of the Users Group provides training for writing user abstracts at the Campbell Colloquia which is open to consumers and researchers.	• The co-chair of the Users Group provides training for writing user abstracts at the Campbell Colloquia which is open to consumers and researchers.
Cochrane Collaboration – Steering Committee	• A free, web-based program on evidence-based health care developed by the U.S. Cochrane Center is available. • CCNet holds a series of workshops in a variety of countries around the world on what it means to be involved as a consumer. • Consumer-focused sessions at the annual Cochrane Colloquium.	• No formal training is provided to researchers.
Cochrane Musculoskeletal Group	• CMSG provides yearly workshops that take place in conjunction with the annual symposium. • A mentoring system is in place which encourages new consumers to take a mentor or to work closely with the Knowledge Translation Specialist the first time they do a peer review. • Consumers are encouraged to take the online course (see above).	• No formal training is provided to researchers.
Cochrane Pregnancy and Childbirth Group	• Training activities are mainly carried out in the U.K., where the editorial base of the group is located, and at the Cochrane Colloquium. • In the U.S., instead of offering training, consumers are provided with an “induction pack” which describes what it means to be part of the consumer panel, why this work is done, what the different parts of a review are etc. • Consumers are encouraged to take the online course (see above).	• No formal training is provided to researchers, but consumer-focused trainings are offered to researchers and consumers at the annual Cochrane Colloquium.

Appendix S10: Formal evaluation of consumer involvement

Organization	**Formal evaluation of the approaches pursued to involve consumers**
AHRQ (EHC Program)	• There has been no formal evaluation so far. • AHRQ is beginning a process of evaluating the EHC Program governance structure; this may include some questions about consumer involvement.
Johns Hopkins EPC	• There has been no formal evaluation so far.
Oregon EPC	• There has been no formal evaluation so far.
Campbell Collaboration (SFI Campbell/former Nordic Campbell Center)	• There has been no formal evaluation so far. • Only the Scottish government evaluated the usefulness of the user abstracts. • The decision to grant permanent funding for the Nordic Campbell Center by the Danish government late in 2008 was, among other things, based on the activities in user involvement that had been carried out up to that point.
Cochrane Collaboration – Steering Committee	• A formal evaluation has been carried out for the activities of CCNet; this was based on focus groups and questionnaires and resulted in recommendations on how the organization could operate more smoothly and effectively and be more integrated into the working of the Cochrane Collaboration. The summary of evaluation is accessible here: http://www.cochrane.org/sites/default/files/uploads/Newsletters/CCNetNewsletter_AppendixJan2010.pdf • Preparatory to a meeting on the Cochrane Collaboration's future strategy on consumer involvement, a background paper was prepared that includes a horizon scanning of what different forms of consumer involvement are applied and what the most important issues are.
Cochrane Musculoskeletal Group	• There has been no formal evaluation so far. • A process evaluation was carried out by holding interviews with some consumers of the Consumer network, but this has not been published.
Cochrane Pregnancy and Childbirth Group	• An independent person carried out an evaluation of different Review Groups, editors, authors and consumers themselves. The results have been presented at meetings, but they have not been published in an article.