

Fact Sheet

Information for Consumer Representatives

Confidentiality guidelines

Consumer representatives are often concerned about how they can consult with other consumers – and be accountable to them – without infringing the confidentiality requirements of their committee. This fact sheet helps consumer representatives decide what is confidential. It is a guide only, different committees may have different requirements and consumer representatives should clarify these with their committee's secretariat. Even where a committee member is not required to sign a confidentiality agreement, they should be aware that confidentiality may apply to some areas of their committee's work.

Confidential information can be defined broadly as information that:

- By its nature is confidential
- Is designated as confidential
- Committee members know, or ought to know, is confidential and includes information contained in any submissions, references or applications to the committee, but does not include information:
 - already in the public domain
 - that becomes public knowledge other than by a breach of the committee's confidentiality agreement
 - is required to be disclosed by statute or court order.

Protecting confidential information

Consumer representatives have a responsibility to store any confidential information away from the public eye until the information moves into the public

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domain, which is usually after the committee's recommendations and report have become public. Even then, parts of the committee's documents and deliberations may remain confidential; consumer representatives must remain careful not to discuss or release any information that is not included in the final published information; for example, details of committee discussions, including who said what. Any documents or other information that a consumer representative receives as a committee member must be used only for the purposes of the committee's work.

Information that can be shared

There is much information that can usually be shared outside the committee to help a consumer representative obtain consumer opinion. For many committees dealing with services and products, this would include:

- The name of the committee and the matter under discussion; for example, the procedure, process, policy, medicine or device
- Membership of the committee, the general scope of the committee (what it hopes to achieve) and the current stage of committee deliberations
- Information in the public domain; such as what is available on websites and in publications. For example, for a committee looking at a new medical procedure, this may include the nature of the medical condition being addressed, what is currently available in terms of treatment and published critiques of the current and proposed treatment
- Comparators being considered in the evaluation (unless it has been identified as commercial-in-confidence); that is, how the committee will compare the matter with similar things. For example, comparators for a new medicine may include dosage, length of treatment, side effects, success rate and cost
- Quality of life issues associated with the medical condition being targeted by the committee's deliberations
- Quality of life issues associated with the technology, procedure etc being reviewed (but only in general terms if the details of the technology are commercial-in-confidence).

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If in doubt about what can be shared, a consumer representative should check with the committee secretariat or chairperson.

Information that cannot be shared

Information that cannot be shared includes:

- Any commercial-in-confidence sections of the information (these should be identified by the committee secretariat or chairperson)
- Information about the committee's discussion or the views of committee members
- Any details of the applicant (including their name) for commercial-in-confidence applications
- Any details about independent evaluators.

If consumer representatives are concerned that information they want to share with their consumer networks may be confidential, they should check with their committee secretariat or chairperson.

Useful tips

Use these useful tips for dealing with confidentiality issues:

- Ask the Chair/Committee Secretariat for guidance on what material is confidential and what isn't
- If confidentiality is applied 'blanket' fashion, raise concerns that this makes it difficult/impossible for the consumer representative to fulfil the role expected
- Clear reports with the Chair
- Prepare a report prior that draws on information available in the public domain prior to commencing on the committee. This helps provide a base

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for consumer consultation on non-confidential material (that can then be used to inform the confidential work on the committee). Look for a way to distinguish between publicly available information and confidential material.

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