

## **Tips for Consumer Representatives**

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Professional and industry groups and so called 'independent experts' are frequently asked for their advice and views on matters relating to the health of the community and individuals. Community and 'lay' people are also sometimes asked to offer their experience to consider matters of public interest in the health arena, such as priorities in resource allocation or the ethics of health services or research. Increasingly government and others are recognizing the need to hear also about the specific interests of consumers in a range of health and community issues. Often, however, the consumer perspective is forgotten or it is assumed that, since 'we are all consumers' it will be well represented by caring providers or those active in the community affairs.

This article gives some ideas about improving our effectiveness as consumer representatives.

### ***Opportunities***

Those of us active in consumer groups need to take up opportunities to represent our perspective on committees locally and nationally and to lobby for representation in places where it is overlooked or determinedly excluded. In order to get our experiences heard and have them contribute to improved practices and better policy, more and more of us need to be available to work on these committees. The Consumers' Health Forum is always looking for volunteers who have an interest or experience in particular conditions and issues. Don't be too shy to offer yourself.

The consumer and community groups we belong to are a good training ground for such committee work. Speaking up and making a contribution in a relatively safe and supportive group builds confidence and skills, but a lot of what you may need to learn will be best done by 'on the job' training.

There are a few simple questions I often need to ask myself when I join a committee (the questions are simple: the answers may not be). Here are a few I have found useful and a few ideas I have picked up along the way.

### ***Why am I here?***

- Is it to lobby on a particular issue, to put forward the particular policies of your organisation or to represent a consumer perspective? If you are not sure, check back with your nominating group.
- Sometimes there will be different consumer interests – for example, people waiting for bone marrow and potential donors; people with grave conditions needing quick access to potentially useful drugs and willing to take the risk of major side effects, and most of us who want assurances about safety before a drug is marketed. Take account of these or seek to get additional representation on your committee for balance.

### ***Where is here?***

- Find out what you can about the committee
- Its membership
- How it works (formally or informally, by consensus or vote)
- Where it fits (sub committee of something else, advisory, final decisions)
- Where the real action is

### ***What will I do?***

- Decide on your objectives in being on the committee (perhaps with your nominating group). You may wish to establish credibility, keep an eye on what's going on. There may be particular changes you want to achieve or you may want the committee's agenda or the way it works to take account of consumer interests.
- An overall plan to achieve your objectives, that is a strategy, may help. Ask yourself:
  - What might be the steps along the way?
  - What barriers have to be overcome?
  - How long should it take?
  - How will I know if I have been successful?
  - What help and information might I need?

### ***How will I do it?***

- Set goals for each meeting.
- Check out the information you are given. Do the 'experts' agree? Can different conclusions be drawn from the same information? Is there information, which consumers and the community have, that needs to be added?
- Look for possibility of forming alliances on some issues with the committee.
- Maintain contact with consumer representatives on related committees. If there are none, work to have consumer representation extended, suggesting your position is merely token unless this happens.

### ***Is there anything else?***

- Read ALL the papers – for the first couple of meetings. It gives you confidence, helps you find your way around, often shows up gaps or conflicts and sometimes reveals real gems which you can use to advantage. Later you may decide you can do some judicious scanning and skipping.
- Ask questions. They can be very revealing and don't commit you to anything. Don't be afraid of looking silly or uninformed. More often than not the query you have will be shared by others. Always listen attentively to replies. If they are not answered pursue the question.
- Separate the issues from the people. Keep focused on the issues in the meeting. What does this mean for consumers like me? For others who are worse off in the health system? In the meeting breaks, lunch, organised dinners, even traveling, get to know the other members, let them get to know you. Understanding motivation and interests may help you formulate argument in the meeting which will 'connect' with others. Others may want to respond to your position if they understand why you are concerned.

- Pay attention to process as well as content. How things are done, how they are recorded, how the information is circulated, who arranges the meetings for whose convenience may make a difference to your effective participation. Bring problems to the attention of the meeting, the chair, its secretariat. If they are not addressed, talk with your sponsoring group. You may be wasting your time.
- Have great expectations – but be satisfied with small achievements. Change is often difficult and it isn't always best achieved by revolution.
- Do the best you can. Be ethical, honest, patient, polite and so on. But when it gets too much, just be yourself!

### **The Eight Consumer Rights**

The right to safety

The right to be informed

The right to choose

The right to be heard

The right to redress

The right to consumer education

The right to a health environment

The right to satisfaction of basic needs

### **What will I need?**

- Humour
- Patience (but not too much)
- Skepticism
- A thick hide
- Some network starters

### **What will I get?**

- Expanded knowledge
- Tired
- Some satisfactions
- Sore bum/sore ear
- Loads of paper
- Confidence

### **What will I lose?**

- Time
- Innocence
- Timidity
- Awe of the system

Good luck. Thank you for being prepared to help.