Raising the Standard: Practice Guidelines and Consumer Participation

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Clinical practice guidelines are increasingly affecting the quality of health care, and have the potential to affect the availability of health care options for consumers. Deciding what guidelines will cover, how they will be developed and what they will say are, therefore, issues in which consumers have a considerable stake. While there is a growing acknowledgement of the need to involve consumers in guideline development, the reality can fall far short of the rhetoric. This article advocates the use of three types of strategies in combination to enable better consideration of consumers' views in the guideline development process: the involvement of accountable consumer representatives in group decision making, community consultation and the use of research literature describing people's experiences. A framework for assessing the level of consumer participation in an activity is suggested. It is argued that if consumer involvement is to successfully raise the standard of health care guidelines, then the standard of consumer participation itself needs to be raised. Copyright © 1996 Elsevier Science Ltd.

RHETORIC AND REALITY

There is a lot of rhetoric about consumers' right to choice in health care. Yet, in many different ways, consumers have shown that they do not always like the options available—or that the services they wanted could simply have been better. When that is so, theoretically, individuals can make suggestions, complain, vote with their feet, or even take things to court. Perhaps they might find themselves being surveyed. Yet how can consumers, collectively, affect the standards in the first place?

Guidelines are common and influential these days and considerable efforts are being put into making them even more so [1–3]. As guidelines are used in determining correct clinical behaviour and people talk about linking performance with funding, the ante for consumers is going up. Guidelines will not just affect the quality of care. They may also determine access to care and the availability of choices. Deciding what guidelines will cover, how they are to be developed and what they say are therefore issues in which consumers have a considerable stake.

There is also a lot of rhetoric about the need for consumer involvement in issues at this level. The reality, though, is that consumer participation in the setting of standards and guidelines lags way behind the exponential growth of other methods and practices in guideline development.

LEVELS OF CONSUMER PARTICIPATION

While the notion of involving consumers is a flag that is waved quite commonly these days, clarity of purpose matched with useful methods is, unfortunately, not so common. People can expect consumer participation to fulfil some very lofty and ambitious goals. The reality, however, can fall far short of the rhetoric. As a consumer advocate, when I hear the words involvement and participation I envisage something much more active than is often intended by those initiating the process at a professional or bureaucratic level. Indeed, much of what others call consumer involvement is played out at such a
minor and passive level that it cannot remotely be called "involvement" at all. This is true even of many examples published by initiators claiming to demonstrate models of good practice. Published evaluations of reactions to some of these models show that they are not so highly thought of by the participants [4].

The rationales for seeking community participation have been described as falling into three categories: to improve services and decisions; to gain legitimation and/or community compliance; or to bring about social change with the redistribution of power or resources [5]. However, even where the intentions are to improve decision making or to empower consumers, the methods put in place usually involve so little participation and at such a late stage in the process, that it would be hard to achieve much at all.

Participation is an active process. Participants should at least have the potential for significant influence. Real participation, indeed, implies sharing of decision making power [6]. Drawing on previous work by others [7,8], Fig. 1 suggests a framework for considering the level of consumer participation in an activity. The lower three levels all place consumers in a passive role, solely as sources or recipients of information, or consulted in a way that allows little room for truly affecting the course of events. The upper two levels indicate where processes open up to provide active roles for consumers. Preferably, participation means partnership from the beginning, not just leaving consumers to try and tinker around the edges of the virtually completed work of others.

Building a good picture of the range of consumers' perspectives and actions means drawing on as many sources of input and information as possible. Essentially, methods for seeking consumers' views fall within three main categories of activity: representatives' involvement in group decision making, consultation and the use of research literature describing people's experiences.

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FIGURE 1. Levels of consumer participation.
In combination, these three types of strategies can enable consumer views to be considered better, allowing consumers to play a key role in shaping health care services. Relying on any one of them alone has serious drawbacks, as each offers different strengths and weaknesses. Depending on the topic, too, the standard of each of them will vary. In many areas of health care, there is not a well-developed level of advocacy and sufficient literature on people's experiences is lacking. Adequate time and budgets for strong community consultation processes are not common. In fact, strength in all three areas at once is pretty rare. Using multiple strategies increases the chances, though, that weaker spots will be compensated for in other ways.

Although many people strongly favour or oppose one or more of these strategies, putting all eggs into just one basket needs to be discouraged. Dismissing the importance and feasibility of consumer participation just because there is not one perfect way of doing it needs to be knocked on the head as well. It is frustrating, for example, to see people interpret "consumer involvement" as "involvement of a consumer"—or equally, to hear that because there is no perfectly representative consumer, consumer representation is not possible.

The involvement of consumer representatives in decision making is important, regardless of how much information about people's views there is to rely on. Ultimately, a lot of policy decisions and value judgements are being made about what is desirable in health care and how it should be put into practice. There is a need to involve people who can concentrate solely on what affects consumers in each discussion, without the distraction of trying to differentiate and juggle their professional perspectives and interests.

Equally consumer representatives need support and scrutiny from others in the community, and the best information possible about how people feel. Discussions need to involve consumer representatives who are accountable to their communities [9], but representatives should not be left high and dry, on their own, with the burden of representing the whole community's hopes and fears.

Commitment to the importance of ensuring that consumers' views have an influential role requires considerable effort. If only limited actions are undertaken, this limited scope needs to be acknowledged.

GUIDELINE DEVELOPMENT: A CHEQUERED HISTORY

The potential and value of consumer participation in the development of guidelines are sometimes acknowledged, albeit that the reasons and roles allotted for consumers vary a lot. At the upper end of the scale, for example, it has been argued that involving consumers can ensure genuine agreement, so that reports do not emanate "merely from agreement forged between a few unrepresentative parties, for example academics and specialists" [10].

The Australian national guidelines' development program goes even further, placing consumer participation at the level of a guiding principle, making it a mandatory element of the process and pointing out: "If guidelines are to improve patterns of clinical practice, produce health changes valued by consumers and be sensitive to variations in individual patient preferences, the development process must incorporate the perspectives and expertise of consumers" [2].

In practice, the Australian system involves public consultation and consumer involvement at all levels, including developing the methodology, and selecting the topics. There is at least one consumer representative on each guideline development group—and a consumer advocate chairs one of them. Consumer representatives are nominated by the Consumers' Health Forum, a national coalition of consumer groups with an interest in health. Some training and support have been available to representatives through the Forum and, more recently, a pilot introductory workshop for all group members offered by the body producing the guidelines. There is financial support for consumers' attendance at meetings. Each guideline development group reviews the relevant literature on people's experiences and concerns (usually employing a consultant for the task, guided by consumer representatives). Draft guidelines undergo a process of community consultation before final acceptance.

This level of consumer participation in guideline development is not yet commonplace. More
often, consumers do not rate a mention in guideline methodology and if they do, it is at a minor passive level. Using Fig. 1, I would classify most of the guideline development processes I have seen described thus far as either having no participation, or enthusiastically embarking on a program merely to manipulate public opinion. Occasionally, people wave the flag for consumer involvement, but do not actually involve consumers themselves.

Consumers make their most common appearances in the guidelines literature not as participants in their own right, but as recipients of professionals’ perspectives or as a vehicle for enhancing implementation of guidelines. Guideline development experts have often turned to consider consumers mainly because patient pressure is believed to be effective in changing professional behaviour [11]. The interest in what are called “patient-mediated interventions” recasts consumers, not as active players, but as the means to affect those (the practitioners) who really matter to the developers of guidelines. If guideline developers see the goal of consumer participation only in such terms, the scope and extent of “involvement” may well stay down the end of the scale. After all, if that is the main objective, you can usually get a long way with just some token consultation at the periphery to get the language right and to get consumer leaders interested and committed, followed by some marketing—especially in a community that is crying out for more information.

This road, however, is one that leads primarily to using community resources for promoting and broadcasting professionals’ opinions and priorities. It does little to ensure that the recommendations reflect consumers’ concerns and priorities in the first place. Yet it ought to be obvious that people who want to use consumers as a tool to change the practice of health care, have a great obligation to ensure that the consumers have a genuine role in determining what those changes should be.

That goal suggests a central role. People who can only contribute at the outer edges of a process are at a distinct disadvantage. It is not necessarily easy to envisage an alternative when presented with a particular fait accompli and it is too late to change direction significantly anyway. Therefore, involvement ideally begins at the earliest stages—including the setting of

the agenda and determining the rules and the players.

Some guideline developers who recommend consumer involvement do not seem to see this as an integral part of the whole process. Rather, it is a kind of “add on” along the way. For example, one group that advocates involvement, describes consumers as possibly being in “particular sessions of the development group rather than . . . in every meeting” [10]. Overall, though, it seems as though recognition is spreading that consumers may be important players in this particular game.

**IS BIAS CREEPING IN?**

There is widespread agreement that a practice guideline development group needs to include those who will be the users of the guidelines if it is to come up with recommendations that make sense. That seems uncontroversial. Involvement of the users of the health service, however, is an idea that still faces some resistance. That resistance seems to come from a few different sources.

The rationale of the current wave of guideline advocacy is based firmly in the “evidence-based medicine” philosophy. Recommendations are meant to be derived from the best possible evidence, not a mere consensus of expert opinions. When this is just a process of scientific assessment, some seem to wonder, where is the need for patients’ opinions? And isn’t the process of bringing in consumers’ opinions just an invitation to that most dreaded of creatures—bias?

In fact, consumer representatives are often strong advocates of an “evidence-based” approach. Faced with competing views or monolithic unchallenged assumptions and interpretations, it is often a consumer representative who will say “prove it”. It is untrue that consumers are inherently incapable of being as objective as a professional. True, consumers have an emotional investment in an issue, but to assume that professionals have no subjective interests or emotions vested in their life’s work is incredibly naive. Consumers are not introducing bias into a hermetically sealed environment; the bias is already there.

Of course, consumers bring different values, and may see issues of “proof” in different ways
as well [5]. This can and should be accommodated in the development of guidelines. In the end, no matter how intensely anyone is focused on objective analysis, levels of judgement must be involved in trying to interpret evidence and in determining how it should be applied in people's lives. Those judgements should not be made by professionals alone.

The concept of consumer involvement in guideline development also touches directly on sensitive issues around professional prerogatives, and an all-too-often low estimation of the worth of consumer participation. All these kinds of concerns are exemplified in this discussion. "But having non-physicians on guidelines panels makes some doctors say ... (one doctor interviewee) worries that the result could be 'politically correct guidelines' that don't necessarily represent the best science, or parameters that emphasize 'warm soft fuzzies' at the expense of appropriate medical care ...." I thought some of those warm soft fuzzies crept into the government's pain guidelines ... When certain non-physicians are put on the team for political reasons, it diminishes the credibility of the guidelines—at least in doctors' eyes." [12]

It would not be in consumers' interests for good recommendations to be overturned because of political expediency and idiosyncratic views. That should not be the consequence of broadly based consumer participation. In any event, the power to make or break a guideline recommendation for political reasons more often emanates from professional societies and colleges than from consumer representatives. In practice, it is treading carefully around professional taboos and sacred cows that predominantly preoccupy the minds of "non-consumer" guideline developers; it often hampers recommendations and strong action, no matter how strong the evidence to support them may be.

Consumers may well be responsible, though, for attempts to incorporate "warm soft fuzzies" into "appropriate medical care"—indeed, I hope we can claim at least some of the credit for that! There should not have to be a choice between cure and care: the goal of best practice, surely, should encompass both. Integrating the reality of humans' concerns and experiences at all levels of health care practice requires no apology; leaving it out, does.

POTENTIAL AND CHALLENGE

For a long time, health care practitioners have spoken on behalf of the people they treat and have, of course, believed that they have done so in consumers' interests. The suggestion that other people are needed to advocate for consumers is inherently confronting for many. For some, this changing landscape will be difficult to accept. It may be easier to dismiss the validity of criticisms, and indeed, the critics.

Comments, such as those about political correctness and "warm soft fuzzies", highlight the fact that many cannot imagine a useful contribution by consumers. Some people simply believe that consumer participation has a cosmetic purpose only. To some, it is the antithesis of science and opening the doors to the community is a backward step that could only lower professional standards.

However, in many places the first steps towards community participation in the setting of health care standards have already been taken. The fact is, these particular doors are already cracking open. The keys to ensuring that consumer involvement can successfully raise the standard of health care guidelines are to open those doors more widely and raise the standard of consumer participation itself.

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