



Involving consumers in health services



'Some studies that were done in New South Wales on so-called unmet needs of cancer patients looked at six large cancer programs and one of the key elements was lack of access to the centre. This came from the consumer interaction—issues of car parking, not understanding what bus routes went past the centre—things that really, while people felt they were important, hadn't been put on a particularly high level. But, in fact, this was really high-level for people trying to get to care, particularly having radiotherapy or radio-chemotherapy where they would have to come on a regular basis, spend some time or be there first in the morning. Access is clearly an important issue for people running services.

As medical practitioners we tend to say, "Well, we'll see you next week at 2 o'clock, Mrs Jones." Whereas, Mrs Jones might not want to come at 2 o'clock next week. She might have family commitments or even elderly parents or other things to deal with. So, what's coming out clear is that people want to determine their own schedule, as much as they can, within the constraints of a treatment program perhaps. They would like to have a say in their scheduling. And I think that's something we still don't do well. But that's a good example of the fact that people want to control their lives and they should control their lives and should be able to have input into how things are given to them in health care. I think there's a real opportunity to engage consumers into building that system to be much more responsive to everyone's needs.'

—Jim Bishop, Executive Director, Victorian Comprehensive Cancer Centre

'If you go back to the first time I came across a consumer on a committee, to where I am now: in terms of the way I work with them, the exposure to them, how we've all learned—I think we've come a long way. In some ways, it's a lot easier for the health professionals not to have consumers involved. But of course it would be much more difficult in that you'd just be creating things for yourself, rather than creating things that people actually wanted. It's harder work, working with consumers, but it's ultimately the right thing to do.

There can be issues [when working with consumers] with making sure the representation is actually broad-enough based and not tokenistic. So you know, you have a token consumer and that person sits quietly in the corner and everyone ignores them and that's not really any use to you. Or you have a really engaged consumer, but who only has one very narrow perspective—that's not very much use to you either. There's a need for consumer breadth, and I think education and up-skilling in the same way that the rest of us have to continuously up skill. We use the Health Consumer Alliance in South Australia to train our consumers and, in fact, we use them to nominate consumers for our committees.

What we've done [when looking for consumers] is we've advertised across as many of our people as we can reach. We have a mailing list for people who have shown interest in the Network. We put posters up in the hospital places. We sometimes even put out a little media release saying we're holding this open forum and everyone is invited.

It's like anything that you suddenly have to do that you didn't have to do before: you have to go into it in a positive, engaging way and be prepared to adjust your position...I try to have as open a mind as I can and to allow room for negotiation and allow room for being taken in a direction that wasn't the one I intended to go in the first place.'

—Dorothy Keefe, Clinical Director, Royal Adelaide Hospital Cancer Centre

