

Examples of consumer involvement



'[We try] to get consumers involved right at the beginning, right at the development of ideas... So you are not just paying lip-service to it, but actually getting them involved.'

A good example would be a highly complex study, funded by the National Breast Cancer Foundation study called the EMPathy study, which is a \$5 million dollar piece of research collaborative around the country looking at on how breast cancer is spread, looking at this really complex scientific thing. And despite the difficulties of this being highly technical, right from the beginning, we got a patient with advanced breast cancer to be there. And she came to every meeting and often she would say, "Oh, I don't know if I can contribute." But she always did contribute and she always brought it back to what was important.

It keeps you honest...You have to actually have consumers as part of the study team. Their names go on the grant. Their names go on the papers that are written. And they are actually part of the study team, rather than a kind of separate advisory team that get fed a little bit of information and then they feed some back.'

—Christobel Saunders, Deputy Head, University of Western Australia School of Surgery

