

PESTER POWER AND NEW DRUGS

'New drugs by their very nature are incomplete products, as full information about their safety, effectiveness and impact on costs are [sic] not yet available.

It is worth noting that enthusiastic support for what is "new" is not the sole preserve of newspapers and can often easily be seen in other media outlets and among the medical and scientific communities.

"Pester power" is a concept normally associated with advertising aimed at children. The question to be asked in this context is, are we witnessing patient pester power or quasi direct-to-consumer advertising, where awareness is raised about new products and patients, charities and indeed clinicians then demand that these products be made available? If this is the case, we need to know more about who is driving this type of marketing, its actual impact on clinician and consumer behaviours and whether it is permitted within the existing regulatory code of practice.'

Wilson PM, Booth AM, Eastwood A et al. Deconstructing media coverage of trastuzumab (Herceptin): an analysis of national newspaper coverage. *Journal of the Royal Society of Medicine* 2008;101:125-32

its effectiveness depends on a particular genetic make-up of the tumour, which is present in only 1 in 5 women with breast cancer. On top of that, the drug has potentially serious side-effects on the heart. Yet patient advocacy, fuelling a media frenzy, led politicians to go with the flow of public opinion: use of Herceptin was officially endorsed with scant regard for the existing evidence or acknowledgement that further evidence concerning the balance of benefits and harms was still awaited.

Patients' organizations: independent voices or not?

Another less well known conflict of interest exists in the relationship between patients' organizations and the

INVOLVING CITIZENS TO IMPROVE HEALTHCARE

'The confluence of interest between advocacy groups, those who sell treatments, and those who prescribe them makes for a potent cocktail of influence, almost always pushing policy makers in one direction: more tests, more procedures, more beds, more pills. . .

As someone reporting in this field for more than a decade, I sense that what's often missing from the debate is a voice genuinely representing the public interest. Sponsored advocacy groups are quick to celebrate a new treatment or technology but slow to publicly criticise its limited effectiveness, excessive cost, or downright danger. And, like many journalists, politicians tend to be unnecessarily intimidated by senior health professionals and passionate advocates, who too often lend their credibility to marketing campaigns that widen disease definitions and promote the most expensive solutions.

The emergence of new citizens' lobbies within healthcare, well versed in the way scientific evidence can be used and misused, may produce a more informed debate about spending priorities. Such citizens' groups could routinely expose misleading marketing in the media and offer the public and policy makers realistic and sophisticated assessments of the risks, benefits, and costs of a much broader range of health strategies.'

Moynihan R. Power to the people. *BMJ* 2011;342:d2002.

pharmaceutical industry. Most patients' organizations have very little money, rely on volunteers, and get little independent funding. Grants from and joint projects with pharmaceutical companies can help them grow and be more influential, but can also distort and misrepresent patients' agendas, including their

research agendas. The scale of this problem is difficult to gauge but a fascinating insight comes from a survey done to assess the level of corporate sponsorship of patient and consumer organizations working with the European Medicines Agency. This Agency coordinates the evaluation and monitoring of new drugs throughout Europe and, to its credit, has actively involved patient and consumer groups in its regulatory activities. However, when 23 such groups were surveyed between 2006 and 2008, 15 were shown to receive partial or significant funding from medicines manufacturers or pharmaceutical industry associations. Moreover, fewer than half of the groups accurately identified to the Agency the source or amount of funding that they received.¹⁷ In some cases patient organizations have been set up by drug companies to lobby on behalf of their products. For instance, one of the companies that makes interferon formed a new patient group 'Action for Access' in an attempt to get the UK National Health Service to provide interferons for multiple sclerosis (see above).^{18,19} The message heard by patient groups from all of this publicity was that interferons were effective but too expensive, when the real issue was whether the drugs had any useful effects.

Bridging the gap between patients and researchers

We drew attention above to problems that can result from patients becoming involved in testing treatments, and ways in which they may unintentionally jeopardize fair tests. As with most things, good intentions do not guarantee that more good than harm will be done. Nevertheless, there are clear examples of the benefits of researchers and patients working together to improve the relevance and design of research. As a result, many researchers actively seek patients with whom they can collaborate.

In an example of the value of collaborative preparatory work, researchers explored with patients and potential patients some of the difficult issues involved in testing treatments given in an emergency. If therapies for acute stroke are to succeed, they need to be started as soon as possible after the stroke occurs. Because they were unsure of the best way to proceed, the researchers asked patients and carers to help them. They convened an exploratory meeting with a group of patients and health professionals, and