

Why the public must be involved in local decisions on medicines funding

By Ed England, a pharmacist at Mid Hampshire Primary care Trust

The Court of Appeal judgment in favour of Ann Marie Rogers in her case against Swindon Primary Care Trust, which had refused to fund Herceptin treatment, challenges the role many pharmacists play in developing policies about the local availability of medicines. As reported in *The Financial Times* for 13 April, the judges said that policies should be capable of being rationally explained and that trusts will still be able to choose between patients as long as they make cost a factor in their decision.

The Department of Health said that PCTs should not rule out treatments on principle but should consider individual circumstances when reaching decisions and should not refuse to fund Herceptin solely on the grounds of the cost of the drug.

Policies and regulations designed to protect the public can give the impression of doing the opposite. A marketing authorisation aims to ensure a product has a favourable risk-benefit balance and a guaranteed quality. However, the granting of a marketing authorisation appears to be slow and cumbersome resulting in the perception that, rather than protecting individuals, the mechanism is putting patients at risk (as many believe in the case of Herceptin). The National Institute for Health and Clinical Excellence appraisal process is in a similar situation.

Evidence-based health care aims to improve outcomes which have meaning to patients, and perhaps this paradigm should be extended to organisational decision-making. Evidence-based health care involves balancing the evidence from research with the patient's perspective and beliefs, and the clinician's professional judgement and expertise. In the absence of national advice local organisations are expected to provide guidance on when it is appropriate to treat or not to treat patients with licensed and unlicensed medicines. These decisions impact on patients' lives and therefore organisational guidelines should also balance evidence, clinicians' experience and the public perspective.

The involvement of patients and the public in decision making is in line with the health reform agenda. In "Patient and public involvement: the evidence for policy implementation", the Department of Health says that "effective patient and public involvement is fundamental to an NHS based on choice,

responsiveness and equity. . . . The involvement of patients and the public in health decision-making is now a central theme of national and local policy in the NHS." The aim is to deliver a health service that is responsive to individual and community needs. The Herceptin case suggests this is not the current situation.

Prescribing and clinical priority committees should involve the public in the decision making process. Often the "medical professions" have taken a paternalistic rather than a patient-centred view, though this is changing as committees may now include patient representatives. It has been argued that all committee members have a patient perspective, although I suggest trust employees would be expected to represent their employers' views and not their own. Independent contractors (for example, GPs and community pharmacists) may not be constrained by

organisational priorities; however they are likely to be influenced by their own personal experiences, cultural beliefs and values. Individuals on prescribing committees (whether employees, independent contractors or patient representatives) are unlikely to be representative of the local community.

Harnessing the support of local voluntary and community groups in decisions about the appropriate use of medicines is one method of involving the public. There is no consensus on what public involvement is, however the creation of partnerships with local voluntary and community groups is essential to successful public involvement and is likely to lead to health developments which meet local needs. Many stakeholders will believe that partnership with the voluntary sector does not represent public involvement because these groups do not represent "ordinary" people. However, the development of partnerships has the potential for these groups to work with the NHS to help improve communication with the public, to help explain the risks and benefits of medicines and help support individual patients.

Local voluntary and community groups should be consulted and actively involved in appraisals of medicines. On an individual patient level, progress is being made on moving from paternalistic compliance towards patient-centred concordance, ie, empowering

and involving patients in decisions about their medicines. The same should now be happening at the local level, where primary care organisations are responsible for improving the health of local people and ensuring equity of access to high quality health care.

Pharmacists have a key role to play in empowering patients and in enabling the public to become involved in making local decisions about medicines. Media reports of the Herceptin case have often taken a viewpoint that has differed from those held by many health professionals. As pharmacists we understand that taking medicines is a balance of risks and of benefits. This perspective and understanding does not always appear to be shared by the public or by politicians.

At the one-to-one patient consultation we are able to interpret and put the evidence into the context of an individual, and discuss the risks and benefits. However, at the organisational level we appraise the literature and make recommendations that are often inaccessible to the public, written in jargon and describing outcomes using statistical terms. We do need to do this. However we also need to interpret the risks and benefits of taking a medicine in terms that have meaning to the public, and which the public and patients can use to make informed decisions.

As pharmacists we should embrace the culture shift towards a patient-led health service. The aim — set out in the Department of Health's "Health reform in England: update and next steps" — is for a health service where politicians set targets and undertake performance management and where continuous improvement is driven by patients' needs and expectations. Active public involvement in the work of prescribing and clinical priority committees is likely to delay decision making. However, the development of partnerships with community groups will improve communication between the public and health professionals, and will, it is hoped, result in health decisions that reflect community needs.

We have learnt from the Herceptin case that in the publicly funded health system explicit criteria should be in place on which to base funding decisions. The days of paternalism in the health service are over, and the public must be involved in local decisions about the use of medicines. I suggest pharmacists are ideally placed to empower individual patients and the general public by ensuring that information about the risks and benefits of medicines is available in an accessible form, so that meaningful health decisions can be made.

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