QUALITY IN HEALTH CARE

Editorial

Involving users of health care services: moving beyond lip service

Despite the rhetoric about “consumer” involvement in the NHS, patients’ charters, and exhortations to seek the patient’s view of quality there remains much misunderstanding about NHS users and their views of the provision of health care. The potential of involving users (patients and their carers) in discussions about the quality of both provision and purchasing is undervalued. Moreover, little attention has been given to developing appropriate methods for assimilating users’ views into both commissioning and monitoring health services.

Users’ involvement in commissioning care

User and carer involvement, when seen alongside the complicated financial aspects of the contracting process, may seem to some to be superfluous, useful only when there is a need to justify a difficult decision, such as rationing services. But involving users of services in commissioning and standard setting will actually improve the quality of those processes by ensuring a focus on issues that are important to users.

The standards that users expect may be different from those of purchasers. A survey of quality standards set by district health services in London found that whereas purchasers were giving fairly clear guidance in specifications for some services, such as maternity services, there were ways in which the specifications fell far short of what many user organisations would demand.¹ For example, more emphasis is placed by users on the risks of cross infection and iatrogenic problems arising from routine care that is specified in contracts.

Users’ involvement and patients’ charters

User and carer involvement is often confused with ideas of individual consumer’s rights – for example, the type of initiatives set out in the patient’s charter. Such prescribed sets of “patient’s rights” are important but are not a substitute for community involvement in wider issues. Even in the process of deciding the content of the patients charter, little notice was taken of the consultation with organised consumer groups. The picture is much the same for local charters; less than half the community health councils in London have been involved in devising local patients’ charters,² and this seems to be reflected nationally.³

Initiatives in patient’s charters are limited because there has been little attempt to involve users in clinical issues or to include discussion of care. It is like a charter

for rail passengers that does not mention trains! A widely held opinion in the health “consumer” movement is that the scope of users’ comments on health services should be much wider than simply views on hotel issues or a “charm school and wallpaper” approach.⁴ Users’ views on clinical issues and the appropriateness of treatment and care should be sought with the same degree of enthusiasm as in seeking patients’ views on the context of their treatment and care.

In London community health councils have raised concerns about the ability of patient charters to improve local services, but health authority managers have expressed enthusiasm for charters, regarding them as management tools for achieving “quality” standards. Of course this would be excellent if the issues addressed by charters were those that are really important for people who use services.

Users’ involvement and provision of care

It is crucial that the views of “lay” people and users of services about the care they receive are heard and channelled into the wider debate about health care. Assessments of the quality and outcome of a service by users and carers may be very different from that of doctors and other health professionals. Patients will feel more in partnership with the professionals if their views are sought about all aspects of their care. People do understand quite complicated medical procedures and clinical issues if these are communicated appropriately; clearly, patients are the best judges of some aspects of treatment and care, such as assessing pain or quality of life after an intervention.

Involving individual patients in decisions about the care they receive is central to good quality care. Mechanisms for improving involvement through outlining patients’ choices and being explicit about the trade offs between alternative courses of action are important aspects of improving the quality of care. But ways of incorporating users’ views into wider issues of quality of care are needed; often the onus is on users themselves to plead to be heard. Alternatively, the contribution of users may be viewed as an afterthought, extrinsic to the “real” business, and sidelined to a relatively junior member of staff to coordinate.

Similarly, the medical audit process has developed without input from users. No guidance has been given about when or whether users should be involved in

discussions about results from the audit process. A survey of medical audit groups and committees in London noted that many of the doctors in those groups and committees were hostile to the involvement of lay people in medical audit.⁵

It is important to differentiate between the direct voices of users and their organisations and the voices of professionals who may have strong views on what serves the patient's best interests. Thus, though general practitioners are able to make valuable comments about the quality of services, their views cannot reasonably be taken as proxies for those of service users themselves. Community health councils, together with their wide contacts among community groups; organisations concerned with particular medical conditions; and a range of other voluntary organisations can all contribute effectively to piecing together the complex jigsaw of user opinion.

There is a clear need for a synthesis of users', providers', and purchasers' views of quality. Users' views cannot be substituted by those of either purchasers or providers, and there should be a redistribution of the

emphasis given to each in the commissioning and monitoring of services, so that users' views are given more credence than has traditionally been the case.

Although there are barriers to integrating users' views into decisions about health services, the benefits of doing so certainly justify the effort that is necessary. It is only by doing so that services can be developed in ways that will be accepted by patients and professionals as beneficial to all concerned.

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- 3 Association of Community Health Councils of England and Wales. *Annual report (1992/3)*. London: ACHCEW, 1993.
- 4 Pollit C. Bringing consumers into performance measurement. Concepts, consequences and constraints. *Policy and Politics* 1988;16:77-87.
- 5 Joule N. *User involvement in medical audit*. London: Greater London Association of Health Councils, 1992.