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Putting patients at the heart of raising quality

Involving patients in clinical audit

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This paper examines whether and how patients might be more involved in clinical audit, and it suggests an alternative, or rather complementary, approach called consumer audit. This gives patients a much more central role, despite the odds being stacked against them in a professional culture which made it acceptable for a 1989 working paper on medical audit to state quite unequivocally that "the quality of medical work can only be reviewed by a doctor's peers."

Things have moved on, and there is now a growing emphasis on clinical, as opposed to medical, audit. The establishment of a Regional Clinical Audit Coordinators Group, the fact that the Department of Health's policy document on clinical audit has had to be reprinted twice to satisfy demand, and the setting up of the UK clearing house on the assessment of health outcomes are testament to the speed of change. There is a real commitment from the top to opening audit up to health professionals involved in patient care other than doctors. But how far this has permeated downwards is a question of how the rhetoric of "patient empowerment," "consumer involvement," "patient focussed care," and so on, is translated into reality.

Who decides topics for clinical audit?

The College of Health recently received a questionnaire from an academic centre for health services research carrying out a survey of audit at the interface between primary and secondary care. The accompanying letter summarised the current position succinctly enough: "Although there is a great potential for audit at the interface between primary and secondary care, there has not, as yet, been a great deal of audit activity in this area." It continued: "Interface audit has potential value in promoting 'seamless' quality in patient care, as well as improving collaboration between health professionals and facilitating effective and efficient use of referrals." However, examination of the twelve page questionnaire disclosed that the word "patient" was used only once – in a question in which "patient/disease management" was classified as one out of six possible categories of interface audit. Next was a question about what triggered the initiation of audit, the options being: a perceived problem, a topic of mutual interest, economic reasons, other, which raised questions of whose perceived problems, whose mutual interests, and for whose mutual benefit?

In reality patients have very little say in what should be audited and are rarely asked to participate in studies of the quality of care they receive. Too many audits are based on patients as cases, as members of diagnostic related groups, as the subjects of medical records compiled by doctors who decide on what it is important to record. They may include what patients were told, how they reacted, and what they had to say about their treatment, but they often do not.

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How can patients or their representatives be involved in clinical audit? The obvious answer would be to appoint lay members to medical or clinical audit advisory committees, but this might involve real dangers – not for the professionals who fear for their confidentiality and anonymity, even though audit committees in trusts or units may balk at the suggestion, but for the lay members themselves in terms of their marginalisation, as illustrated in the following example.

In May 1989 the *Institute of Medical Ethics Bulletin* contained an editorial which stated:

> The consumer voice in medical ethics in this country has always been surprisingly muted. The need for a consumer voice has, of course, been recognised in the field of research ethics. Yet fifteen years after DHSS advice, there remain ethics committees without a lay member. And the anecdotes that come out of some of the other committees suggest that the consumer voice is not so much muted as strangled.[1]

A month later, at a workshop for lay members of ethics committees run by the College of Health and Riverside Community Health Council, it became apparent that this was no exaggeration. Twenty eight people attended the workshop, most of them from community health councils and 18 of them lay members of ethics committees. Two of the community health council secretaries said that

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their districts had no ethics committee at all, and another that they had no formal ethics committee but there was an informal group of consultants who met in the doctors' club at the local district general hospital. Others reported that their committees met rarely, if at all, but conducted most of their business by post.

One community health council member reported having been appointed to the ethics committee nine months previously but having received no papers since then and having been unable to find out whether meetings were ever held. Another member had been told that meetings were held in an ad hoc fashion and so there was never time to contact lay members in advance.

In several places the so called lay member was a retired doctor or nurse, or someone such as a hospital chaplain who was employed by the district health authority. It was also rare for there to be more than one lay member and, not surprisingly, this made lay members feel vulnerable. In discussion it emerged that some lay members are treated like idiots if they cannot understand obscure terminology, despite the fact that if researchers are unable to communicate to lay members of a committee the intention of a study they are unlikely to succeed in explaining it to a patient – who, in the nature of things, is more vulnerable and anxious and yet is expected to give informed consent.

One of the main conclusions of the workshop was the urgent need for training and support for lay members of ethics committees, although this was unlikely to be met because of a lack of specific funds. Fortunately, money should be less of a problem to audit committees with the £3.2m provided to pump prime multiprofessional clinical audit. However, before rushing in to appoint consumer representatives to clinical audit committees those who hold the purse strings should think seriously about the need to develop appropriate training and support networks for those lay representatives. In Oxford region, for example, the Department of Health is funding the production of open learning materials for lay people involved in formulating and implementing health policy, and in Wessex region the regional medical audit team is discussing the concept of patient panels to help with standard setting, and training will be an important part of this.

With better funding and training ethics research committees could have a much more important role in the transition from the rhetoric to the reality of putting patients at the heart of raising quality. That ideal goes to the heart of the question of how open and accountable we are to the patients who are the subject of our research.

Openness and accountability

All patients whose treatment will form part of a research project, whether medical, nursing, or, now, clinical audit, should be informed about the nature and purposes of the research, and their consent should be sought if access to personal information about them is involved. There could surely be no better way of making sure that consumers are aware of the existence and purposes of clinical audit. But it also follows that if patients are to be asked for their consent – as they must be before taking part in a clinical trial — there would be a role for ethics research committees in considering and approving some clinical audit studies beforehand. As things are I suspect that many people assume that only research entailing "hands on" treatment of patients need be referred for approval.

Clearly, there are resource implications, but by March 1994 £220m will have been spent on developing clinical audit, the lion's share – £160m – on medical audit alone. In the interests of public accountability as well as ethics, patients who are the subject of research, as well as the taxpayers who fund it, ought also to be able to share in the results. Should it not be standard practice for ethics research committees and for clinical and medical audit advisory committees to publish, or at least make publicly available, a report of the results of studies they have approved? Indeed, in the spirit of the patient's charter, health authorities or directors of public health might also publicise summaries of such studies in their own annual reports.

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It is shocking how little is known about the reasons behind the undoubted variations in the use and outcome of clinical interventions. People are classified as discharged or dead, depending on which way up they leave the hospital, but it is not recorded as a matter of course whether those who did not die got better or how much better they got. By and large, this is because they are not asked.

Consumer audit: a complementary approach

A complementary approach to clinical audit has been developed at the College of Health over the past five years or so, which is called consumer audit. It involves a range of qualitative methods, centred around in depth interviews with patients and carers in their own homes, but also interviews with staff at every level, including some staff such as medical records clerks and secretaries who are not used to being consulted. The college staff observe anything and everything they are allowed access to. They conduct focus group discussions with members of voluntary organisations, with ethnic or cultural minority groups, and with others who are potential users of services but have not gained access to them for whatever reason. The thirty or more consumer audit studies conducted across a

wide range of acute, community, and primary health care settings have never yet failed to come up with findings which surprised the clinicians and managers who commissioned the research and to lead to immediate changes in practice. These changes did not necessarily cost much money to implement since they so often entailed improvements in the quality of communication and information rather than expensive new fabric or equipment. We have learnt that those best placed to inform about access, process, and outcome – some of the key elements of clinical audit – are patients themselves.

The following are some examples of the type of disclosures that result from allowing patients to set their own agenda in the course of in depth interviews and focus group discussions about their experience and views about health care.

Underlying realities

ACCESS

One way to assess access is through statistics of hospital waiting lists. Recently these have shown a welcome downward trend for those waits exceeding two years, but what is the reality behind the statistics?

In a survey of gynaecology services for one district on the south coast, we found that the statistics were misleading. By national standards the waiting times for admissions were quite good: no patient had been on the waiting list for more than a year and most patients were admitted much sooner, after having seen a consultant in the outpatient department. But it soon emerged from the interviews that for many women the problem had been the initial referral because their GPs did take their problems seriously. Some women had been having problems for up to ten years and had had to give up their jobs, quite apart from having no social or sex life. One woman, who was reduced to wearing babies nappies, was told by her GP, "Look you're a woman. It's just part and parcel of it. You've got to put up with it."

Much the same story emerged when we interviewed fifty people who were waiting for hip or knee replacements. The health authority was worried enough that they had been waiting for admission for two years or more to ask the College of Health to find out how this had affected the quality of their lives. The reality was, again, that some of them had been in great pain for years before they had persuaded their GP of the need for referral.

The two examples show the need for studies of the interface between primary and secondary care. In both of these consumer audits the college's recommendations included the setting up of referral protocols between consultants and GPs.

Many issues were raised by the orthopaedic patients in their interviews, some of which would be unlikely to have been disclosed by a clinical audit. The following illustrates one such example. Some patients had been taking up to, and even over, the maximum recommended dosage of strong painkillers over many years and yet were still in pain. Some had had to stop taking painkillers because they had developed conditions such as ulcers or hiatus hernia, and some were trying to manage without any painkillers and were crying out for advice on non-drug forms of pain relief. We recommended that all those concerned with pain relief – consultants, GPs, pharmacologists, pain clinic staff, and so on – should come together to draw up a protocol of best practice, taking into account the needs of people who cannot take analgesic drugs for whatever reason and making sure that they are given information about other methods of coping with pain and how to access them.

PROCESS

One of our consumer audits looked at the day surgery facilities of a hospital which is justifiably proud of the way it has been able to bring down long waiting lists. It illustrates the fact that the conveyor belt approach can be taken too far. In this hospital the policy on transporting patients from the day surgery ward to theatre had been changed to ensure that the surgeons were never kept waiting for patients and also to reduce the numbers of porters and nurses needed to escort patients to the waiting bay outside the theatre. Not only did this save money but the surgeons regarded it as essential for them to keep up their working pace. They did not see it as causing any problems for patients. This, however, is what two of the patients had to say.

> Previously, you just went straight in, but now you're taken by wheelchair to the waiting bay and put on a trolley. There's up to six people in there and sometimes not enough room. You lie on the trolley for I don't know how long, but up to one and a half hours. The most annoying thing about it all is waiting in there, in the overload bay – not all that warm, sometimes freezing cold – with just one blanket. I'd rather be up and about than having to lie there looking at the ceiling counting dead flies in the light fitting, and that's no joke.
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> We were put in there and I got onto a trolley. The first time I waited about an hour and a quarter with no glasses on, so couldn't see, and no teeth, so couldn't talk properly. I'd like to stick the hospital manager on there and see how he liked it. It was the worst part of the whole experience.

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By allowing patients to say how things were for them, rather than just asking them to tick boxes on questionnaires designed by people who have their own set ideas about what the problems are, there is no doubt that valuable information can be obtained on what may

seem to be relatively unimportant details but what is crucially important to their impression of the service provided.

OUTCOME

Our study of the quality of life of the people waiting for hip and knee replacements showed clearly that patients' views need to be sought but that under the present system they may be lost. When I conducted the follow up interviews I was struck by how worried several of the patients were some three to four months after their operation about how slow their process of recovery had been, about how much less they were able to do, or how much more pain they were still in than they had expected. It did not help that each had been for their postoperative check up at around six weeks but had been seen by a junior doctor, rather than the consultant; each had had very little time with the doctor, and in a couple of cases, had not been examined at all but had been reassured, not helpfully in the circumstances, that they were doing fine. These patients had not been given any further follow up appointment, and I felt very uncomfortable when several of them pressed me to tell them whether I thought they were progressing normally, by comparison with all the other patients I had interviewed. In fact, especially with some of the younger and apparently fitter patients, I was rather shocked by their lack of progress and certainly by the lack of information or offers of further follow up. Owing to the way the system works, there was no way in which the consultants concerned would have known of the disappointment and concern of these patients. In all probability their records showed that the operation went well, the patient had been discharged, and that the junior doctor found nothing untoward at the follow up appointment, and that is all the hospital was likely to know of the outcome.

If some of what appears in the college's consumer audit reports seems to be unacceptably anecdotal, to centre too much around the problems of individual people, I would contend that to audit effectively you need to know how patients perceive their treatment and its outcome. Otherwise health care services will fail to serve their real needs.

It is especially important in today's NHS to find out how the services work for vulnerable people who need protection and who need advocacy. Such people need to be consulted and to know that their views are going to be taken seriously. They need to be given positive proof that audit in the NHS is done, not just to save money or increase throughput, but genuinely to improve the service that they, the patients, receive. Involving patients in a serious way in clinical audit would indeed put them at the heart of raising quality.

1 Anonymous. Editorial. *Institute of Medical Ethics Bulletin* 1989;No 50:1.