Consumer and professional standards: working towards consensus

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Abstract

Standards of treatment and care should be acceptable to healthcare consumers as well as to healthcare professionals. A simple categorisation of standards according to their acceptability to consumers is outlined. Professional/consumer groups which review and set standards are discussed, with emphasis on the principles of partnership. Working together towards consensus can be difficult but is now an important way forward.

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It might seem axiomatic that those who give health care and those who receive it should be agreed about what standards of treatment and care are acceptable. Each has a crucial interest, or stake, in standards—the one for their satisfaction and repute in their working lives, the other for their welfare and even their very lives. However, although patients have a greater stake in standards than health professionals, healthcare professionals have the power to reject patients' views about what standards should be. Yet there is much current emphasis on consultation with healthcare consumers—that is, patients, patient groups, and patient advocates—and much research into patients' satisfaction with their care and attitudes towards it.^{1–3} It may therefore be useful to consider standards from a consumer point of view; to categorise, however simply, standards by their acceptability to consumers; and to highlight one of the ways through which consensus or agreement over standards between professionals and consumers can be reached.

Standards as seen by healthcare professionals and healthcare consumers

We think of standards of treatment and care as central to health professionals' endeavours to do good. Professions formulate standards through their national professional organisations—their councils, Royal colleges or associations—or through specially convened groups of their members. Local groups of professionals debate standards and decide which

to implement collectively, and individual professionals also have some discretion or power of choice of standards. Professional bodies compare the practice of individual professionals with professional standards in deciding matters of accreditation or discipline. Governments announce new standards. Standards are a currency of discourse and a guide to professional action.

Standards are descriptions of specific aspects of healthcare practices to which are attached prescriptive values. Those values may be quantitative ("Patients post myocardial infarction should be treated with aspirin 75 mg daily unless contraindicated")⁴ or qualitative ("You must respond honestly to any questions the patient raises and, as far as possible, answer as fully as the patient wishes").⁵ The descriptions are of actions carried out by the particular profession, though some of the actions overlap with those of other health professions and of ordinary life. But the values can be drawn from any field of knowledge or thought, from the highly technical to the everyday, from scientific research to psychoanalysis, from ethics to evidence, from empirical certainties to professionals' intuitions and beliefs from their experience.

No single group of people has unique access to a specific value or set of values or can be said to own them: anyone can consider and advocate any value or set of values. The freedom of values as ideas open to everyone allows the values attached to practices to be changed as new knowledge, new sensitivities, new social pressures arise or new practices develop. But professions adopt specific sets of values that they consider theirs and accept as guides to thought and action. Which values they adopt is partly a matter of utility, partly of power. The more powerful a profession, the more freely it can choose values that suit its members and that they believe best sustain its ideological and practical missions. For example, general practitioners in the UK believe that they protect patients' interests by acting as gatekeepers to patients' access to secondary care, a belief not held in many other countries nor by all patients in the UK. Within each profession there is always some dissent over what values should be attached to certain practices. However, broadly we can speak of professional

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standards—those accepted by the profession nationally or locally, whether published or unpublished. The more closely a profession harmonises its values with those of the wider society of which it is a part, however, the more it will be trusted and seen as a force for good.⁶

These professional standards are, however well meaningly, generally imposed upon patients. Even when patients can choose their professionals, their healthcare setting, and their treatment, they are affected by a multitude of practices carried out to values they can seldom directly influence and may not even be aware of. (Practices and their associated prescriptive values will from now on be called standards.) It is therefore hardly surprising that patients and professionals disagree over what some standards for non-clinical care, clinical treatment, ethics, and professionals' behaviour should be. Indeed, it is patients' dissatisfaction with some professional standards that has led them from the 1960s onwards to form patient groups, thus laying the foundation for the health care consumer movement in the UK and elsewhere.⁷ The continuing dissatisfaction of patients sustains the movement.

The health care consumer movement can be thought of as shadowing the professional side of health care, as an opposition shadows a government in power in western democracies. Just as a profession or a political party is composed of individuals with different though overlapping expertise, so is the consumer side of health care.⁸ Patients are the experts in their own experiences of health care, but their usually limited experience hinders individual patients from representing or speaking for the views and interests of other patients. The expertise of members of a patient or consumer group lies in their continuing concentration on the experiences of patients in their particular care group and their detailed knowledge of what issues, practices, and standards are of concern to those patients. The expertise of patient or consumer advocates lies in their knowledge of issues across patient care groups and their ability to apply the principles that protect patients' interests to both specific and general issues. Thus, patient group members and patient advocates can speak from wider perspectives. Neither has perfect knowledge of the views of all patients, any more than any single doctor or nurse knows exactly what all other doctors or nurses think, but both can contribute informed discussion from identifiable perspectives, just as different health professional groups or factions within a governing party do.

Just as an opposition agrees with some government policies but criticises others, so do patient groups, patient advocates, and patients accept and, indeed, praise some professional standards but deplore others. Like health professionals, the consumer side of health care has access to values from every field of human thought, but it has better access than many professionals have to patients' reflections, analyses, and judgements on their experiences of health care. At the same time, the movement is fragmented in two senses when compared with the professional side of health care.

Firstly, its shadowing does not cover in detail the total range of health care, and there are some conditions and situations for which no patient groups exist. Secondly, different patient groups address different aspects of health care, some concerning themselves mainly with non-clinical care and standards while others are concerned with clinical care. Yet both are important. Both need to be subjected to patients' judgements of their experiences and both need to be subjected to study by patient group of those judgements together with their study of other opinion, research, and evidence. Health professionals sometimes feel doubt about which patients, patient groups, or patient advocates they should listen to.⁹ Patient groups, patient advocates, and individual concerned patients are luckier; they can tap into published works by professionals and judge them on their merits.

There is also a kind of fragmentation that the consumer side shares with the professional side of health care—disagreements and conflicts of view. These are to be expected for all issues for which there is no well founded evidence that one course of action is more effective and more acceptable to patients and professionals than all other courses. In any case, patient groups vary widely in their scope, their relationship with professionals, their use of published sources of evidence and opinion, and their ideologies.^{10 11} Professionals also have different perspectives, priorities and sets of beliefs, not just between different professions but within the same specialty in the same profession.¹² However, just as the professional side of health care has enough commonality to allow generalisations to be made about professionals, so has the consumer side. Thus, we can make certain generalisations about the acceptability or unacceptability of professional standards to consumers.

Categorisation of standards

To assess the acceptability of standards, a systematic approach is desirable. Categorisation can help. Health professionals know what standards are current in their clinical workplace. They may be supposed to accept those standards even though they may seek, individually or collectively, to change some of them. One way of categorising standards is therefore by whether or not consumers, particularly patients, are aware of certain standards, as well as by whether they think them acceptable or would think them acceptable if they knew about them. Here is such a categorisation:

A. CLOSED STANDARDS

Standards that most consumers are unaware of but that most professionals regard as non-problematic or good.

- A1: standards that most consumers would regard as good or non-problematic if they were aware of them—for example, the regular reporting and auditing of critical incidents in operating theatres or the checking of all drugs and equipment before each patient arrives.¹³

- A2: standards that most consumers would criticise or seek to change if they knew about them—for example, continuing to work to specific clinical routines after it has been shown reliably that other routines are both more clinically effective and more cost effective¹⁴; retaining organs and tissues post mortem without the knowledge and consent of relatives¹⁵; writing “do not resuscitate” orders for competent patients without consulting them first.¹⁶

This A2 category includes some practices and standards that consumers are likely to judge scandalous, not merely unsatisfactory. It is sometimes hard to tell whether some “back-stage” practices that take place outside the direct observation of patients and without their knowledge are covered by professional standards or are deviations from such standards. In general, they seem to be professionally accepted standards in which clinical or ethical values have been sacrificed to other considerations. Operating on babies earlier than clinically necessary in order to gain experience of a very young age group¹⁷ or taking and keeping organs post mortem from children without their parents’ consent were standards in which ethical considerations were subordinated to those of training and research.

B: OPEN STANDARDS

Standards that consumers are or easily could be aware of.

- B1: standards that consumers judge satisfactory or good. Most standards at any one time come into this category but new knowledge or the changing perceptions of patients or interpretations of their experiences of health care can move standards out of this category. A complicating factor locally can be questions round the compliance of professionals individually or collectively with agreed standards or about their competence—that is, questions of performance. These issues, though analytically distinct from issues about what standards should be, can overlap with them.
- B2: standards that some or many professionals regard as satisfactory or good but that consumers criticise or think unsatisfactory—for example, excluding parents from their child’s recovery from anaesthesia¹⁸ or entering patients into clinical trials without their knowledge and consent.¹⁹

These are the standards that patients find distressing either as they experience them or as they reflect upon their experience of treatment and care in the light of subsequent knowledge or subsequent experience. These are the standards that patient groups and patient advocates seek to change, often through long campaigns.

Working towards consensus

An early step in working towards consensus should be to bring the *closed standards* of A into the open. Then their acceptability can be categorised as B1 or B2.

The easiest way to bring closed standards into the open is to ensure that consumers can

have ready access to copies of departmental or general practice policies, standards, protocols for procedures, and guidelines for clinical situations and treatments. When there are merely informal understandings within a department about what should be done or not done, these understandings should be made explicit in policies or guidelines. Both patient groups and individual patients need easy access to all statements of standards, policy documents, and guidelines. Patient groups can then consider matters in depth and contribute to informed debate about the standards in the documents, and individual patients, who are in a more immediate and vulnerable position than members of patient groups, at least have an opportunity to try and ensure that their interests, as they define them, are protected.

An example of keeping a standard closed comes from the 1980s when some coronary care units had age related criteria for admission but did not make them public, so elderly patients and their general practitioners did not know that they should seek admission to other units.²⁰

An example of opening a standard comes from the Royal College of Anaesthetists’ guidance that maternity units should tell pregnant women in good time exactly what anaesthetic service the units offer, so that women can take that into account in choosing where to have their babies.¹³

Standards that are *open* can be discussed by consumers and professionals together at every level of the health service:

- *nationally* in the national professional organisations responsible for articulating national standards⁹ to review and set standards that should apply throughout the country;
- *locally* in working groups sponsored by the bodies responsible for providing health care, NHS trusts, health authorities and primary care groups, drawing on local patients and patient groups for members to add local standards to national ones to suit local circumstances in hospital wards, departments, and general practices;
- *individually* between patient and doctor or nurse or other health professional as part of the discussion and agreement about treatment and care that takes place within the clinical relationship. Although organisational standards can seldom be changed quickly to meet the wishes of individual patients, they can often be implemented responsively. However, certain of the standards in clinical guidelines could be a matter for discussion and negotiation between the professional and the patient.

The principle of partnership

In all these working groups partnership between consumers and professionals should be the guiding principle. Partnership means that all participants have an equal say and take part in decisions. Even when a decision goes against a consumer position, that position is voiced at the time the decision is taken, just as a profes-

sional position that does not find favour is voiced at the time in all-professional discussions.

The growth and differentiation of the consumer side of health care means that it is now feasible to appoint to professional committees consumers who, like the professional members, can be matched to the task and level of the group.⁹ Patients and patient group members can be invited to working groups or liaison groups with local professionals to discuss standards in their local services.²¹ At the national level most of the medical Royal Colleges now have patient liaison groups made up of doctors and patient group members and patient advocates.⁹ At the level of specialist public bodies such as the Committee on Safety of Medicines “representatives of patients’ interests”, usually patient advocates, are being appointed for the first time.²² These are important steps in giving consumers an active role in discussing issues with those who have the power to make decisions, not merely a passive one through surveys of their opinions.

It is true that such professional committees with consumer members are still the exception. The number and spread of working and liaison groups at the local level and at the national level in the national specialist organisations is still low. The appointment of people from the consumer side can be problematic; professionals sometimes choose individuals who are ill fitted for the task.²³ In some groups and committees there are not enough consumer members to cover the range of knowledge and expertise necessary to meet that amongst the professional members. Some patient advocates and patient group members are in such demand to serve on professional groups that they risk losing touch with their patient group colleagues and the patients whose experiences are fundamental to the consumer side of health care (Jean Robinson, personal communication). Professionals and politicians also face this risk of becoming remote or “unrepresentative” as their constituents see them. If the consumer members are in a minority in a working group or committee, they can be marginalised by the professional members.²⁴ If members are in clinical relationships with each other or if the professional members think the consumer members are criticising their personal practice, difficulties are likely.⁹ Keeping up with research papers, official documents, and wider thought and opinion can be time consuming and expensive, especially for the consumer members who usually lack administrative support and more than minimal expenses. Some consumers and professionals are not good at handling the inevitable conflicts of view that arise over some standards—standards can arouse strong feelings including feelings of hostility towards those of a different view—or consumers and professionals may reach a consensus that other consumers or professionals would regard as retrograde. Like all of these problems, this is a risk in any discussion or decision making group.

Helpful factors, on the other hand, include the willingness of many professionals to engage

in such discussions. Most importantly, there are always some crossovers or lack of sharp boundaries between professional standards (those recommended by professional bodies which most professionals work to) and consumer standards (those most consumers would like to see implemented). New standards may be articulated by either a few consumers or a few professionals and then advocated by either or by both.⁷ Many of the standards consumers want to see in place correspond with best practice as leading professionals define it. Or consumers can raise issues that all-professional groups might avoid. This allows professionals to voice doubts or aspirations that may find alliance with those of fellow professionals as well as of consumers.

Although health professionals have often been slow to accept and adopt specific standards that consumers have wanted to see in place, however poignantly patients have complained and however cogently patient groups have put forward evidence and argument, there is a slow but steady move towards acceptance by professionals of many of the standards for which consumers have pressed.^{7 25} This is evidence that consumers and professionals can reach agreement on standards, even though agreement has often been implicit rather than negotiated.

Some consumers have been in touch with sympathetic professionals ever since the consumer movement began in this country and have worked through them to try to bring about changes to standards.⁷ The more structured approaches outlined here are a formal continuation of that. There are other ways of alerting professionals to patients’ views on standards, such as surveys and focus groups, but they tend to leave the discussion and final decision about standards wholly in the hands of the professionals. Some excellent research into the views of general practitioners and patients about indicators of good general practice in Holland, for example, found much consensus but some significant differences.²⁶ The authors concluded, however, that the doctors’ views should prevail. There seems to have been no direct discussion between doctors and patients about each others’ values and priorities or exploration of whether both could be accommodated.

In contrast, the essence of the partnership approach described here is in its potential for collaboration between professionals and consumers and the sense of shared enterprise and responsibility for defining standards that other consumers and professionals will find acceptable. Sometimes the movement of standards forward will not be as far or as fast as some consumers would wish; that is in the nature of negotiated agreement. But ideas initially dismissed can prove acceptable later. Indeed, the consumer members of professional/consumer groups can act as early warning systems, identifying issues and concerns among patients that will increase in salience unless professionals accept that standards should change to meet those concerns.²⁷ This may pre-empt major dissatisfaction and help keep professional

standards up to date with wider social values and expectations.

Conclusions

There will always be some differences between professional and consumer views of standards. However closely professional and consumer values, interests and definitions overlap, some conflicts will remain or will emerge with changes in health care and social values and expectations. There will always be patients who will identify from their experience of health care divergences between their values and those embodied in standards and who will find common cause with other patients. But although consumers remain fragmented, under-resourced and dependent upon the multitudinous voluntary commitment of individuals and groups, there are promising moves towards increased collaborative working with professionals. The number of professional groups that include consumers is rising.⁹ Patient groups and organisations are setting up training in analytical and advocacy skills for their members.^{28 29} The theoretical underpinning of the health care consumer movement is becoming better articulated.²⁵ Organisational resources to support the consumer side of health care are likely to increase, as they have in countries like Holland and Australia.¹⁰ Professional perceptions of the contributions of consumers to health care are changing. A doctor, referring to partnerships with "lay" people, recently wrote: "We no longer think that doctors can or would want to have sole responsibility for professional standards . . .".³⁰ The challenge now is to develop and extend ways in which consumers and professionals can review and set standards together and so work towards greater consensus between the professional and the consumer sides of health care.

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