

# Who are you, and who are we? Looking through some key words

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### Abstract

The terminology used to describe individuals who come into contact with health services is problematic. Many of the most commonly used words, for example, patient, consumer, user, carry overtones or imply characteristics, which may be misleading or unacceptable to those to whom they are applied.

### Introduction

#### Patients as partners

The last few years have seen important changes in the relationships between health professionals and the people they serve, at least in Britain and other industrialized countries. A generation or two ago most doctors, nurses and other health professionals made little or no attempt to share decisions with their patients or others whom they advised. They knew best, and expected their advice or their orders to be followed. Now it is increasingly recognized that most people need and benefit from a more equal relationship, and patient empowerment, even patient partnership, has become a major element of policy throughout the National Health Service. These changes have made some traditional terms unpopular and have led to a search for new ones that convey the desired power relationships. In this article we discuss the use of some widely used terms, and suggest ways of using them more thoughtfully. Two points deserve emphasis at the start. The first concerns the mistaken assumption still made by most lexicographers that the multiple meanings of many common words

can be sharply separated. Empson's painstaking analyses have shown that several of a word's multiple meanings can be present at the same time, and that then the strengths of the 'secondary' meanings depend on the context, often quite subtly.<sup>1</sup> The other point is that many of the terms we will discuss denote roles rather than different categories of people. It is normal for any individual to have more than one role at different times, or even at the same time, and role conflict is not uncommon amongst health professionals. An obvious example is the doctor or nurse who is or becomes a patient, or a nurse who in her role as patient advocate is in conflict with a senior medical colleague.

#### Patient

Traditionally doctors, nurses and many other health professionals talk about their 'patients'. That is their term for those who come to them with an illness or a symptom, for advice and treatment. The problem is that the word 'patient' carries resonant historical and emotional overtones: its etymology includes the meanings 'grief, want, hunger', from which follow supplication, passivity and inferior status as well as suffering

and endurance. The suffering includes the unpleasantness of being talked down to. To *be* patient is to have the ‘capacity for waiting without complaint, and bearing without restlessness and over-eagerness, delay in the accomplishment of what one expects and desires to happen’.<sup>2</sup> So these overtones resonate also in out-patients’ clinics: patients are supposed to be *patient* even if there is a 2-hour delay to see the consultant. Waiting lists, again, are only to be expected, and to be endured with fortitude.

Even hospital signs to ‘out-patients’, in themselves neutral enough, may arouse feelings of foreboding in those who attend for consultation. What will be found? How will one manage if some dread disease is discovered? People may then become, in the words of popular journalism, ‘sufferers’, or worse, ‘victims’. This reinforces the supplicant position, invoking pity rather than empathy in the beholder. But it takes strength of character on the part of the person with (say) cancer to insist on equal partnership with health professionals in the choice of treatments, and not to collude with the prevailing ‘poor you/poor me’ attitude. Alternatively, the patient may be jollied along with injunctions to ‘think positive’ and adopt a ‘fighting spirit’ when s/he may be in shock after a bad news interview.

But in fact many people who consult health professionals are not actually ill – most women who want advice on family planning or contraception or on managing their pregnancy are healthy, and so are people who need immunizations or other preventive measures. It would be cumbersome and tedious to describe such people as seekers of advice on reproductive health, or on disease prevention. They are more appropriately called clients or health service users.

### Client

The current edition of Fowler’s *Modern English Usage* states:

A person using the services of a professional person – a lawyer, an architect, an accountant, etc. – is a *client*. At the other end of the social scale, a person availing himself of the services of a prostitute is also a *client*. Social workers describe the people they assist as *clients* (not

*cases* or *patients*). A person purchasing items from a shop is a *customer*. ...Hairdressing salons call their customers *clients* rather than *customers*.<sup>3</sup>

There is thus a strong case for using the word at least for healthy people who consult a health professional. ‘Client’ has overtones of professionalism, expertise, mutual respect and social parity, though in the case of prostitutes and hairdressers the use of the term perhaps sounds slightly inflated. In medical practice the word still feels a bit odd, except in practices dealing largely with healthy people, e.g. cosmetic dermatology or surgery, and contraception. It is probably more widely used by psychologists, psychotherapists, and professions allied to medicine including practitioners of various forms of complementary medicine. A person visiting a pharmacy is usually a customer, but one who consults a pharmacist then becomes a client as well. She or he may also be a patient. So the three terms are not mutually exclusive, but describe overlapping roles and relationships.

### User of health services

This is a neutral catch-all term for all those who use or have used any health service, public or private, and is easily extended to include potential users too – that is everybody. However, some people do not use it because it may carry overtones of drug use or misuse. Also the term tends to denote client groups who are disadvantaged in some way (for instance wheelchair users) and who use social services rather than the health service. The word citizen also covers everybody whilst encompassing all spheres of activity, not only health and illness, and hints at civic responsibility, as in citizens’ jury.

### Consumer

On the face of it this word means the same as user, but its connotations differ. This is evident from the two meanings given in Collins’ *English Dictionary*:<sup>4</sup>

1. a person who purchases goods and services for his own needs; 2. a person or thing that consumes.

The commercial overtones of the first meaning displease some people. The word also evokes connotations of consumerism, defined as 'the protection of the interests of consumers'. This gives it a slightly assertive, even militant edge, suggesting that consumers of health services are more likely to insist on their rights than mere patients or users. The word is therefore particularly apt in connection with research ethics committees, health authorities, funding bodies and the like, where consumer voices are increasingly given parity with those of the professionals. It does however, have the same universality as user: we are all consumers, whoever and whatever else we may be.

#### Terms for specific kinds of patients/users/consumers

It is often necessary to refer to a particular group of people, for example pregnant women, people with epilepsy, psychopaths, black people, gay people. In doing so it is obviously desirable to avoid offending the people concerned, their family and friends. A useful general rule is to avoid words that characterize people only in terms of their disease or disability because this ignores, and so seems to deny, all their other individual personal attributes. It is therefore better to speak of people with epilepsy than of 'epileptics', of people with cerebral palsy, not 'spastics', and of people with learning disability, not 'the educationally subnormal' or 'idiots'. It is argued that what terms are acceptable should depend on the views of the affected people themselves, but the risk of such political correctness is that not everyone will understand the preferred term. For example, the fairly subtle distinctions between 'blind' and 'partially sighted', or 'deaf' and 'with impaired hearing', or 'crippled' and 'physically handicapped' will escape many who are not used to making such distinctions.

#### Participants in medical research

So how do we describe people who are recruited into clinical trials? (The word 'recruit' has

military connotations, and patients become foot-soldiers in the 'war' against cancer and other diseases.) Traditionally, such people have been called 'subjects', a word redolent of passivity and subjection, and being ruled by some overlord. Yet many medical journals regularly use this word with no hint of irony. Of course it depicts what actually happens in many clinics where patients are recruited into trials, and too often agree to join in because they don't wish to offend the doctor who is treating them, and who seems to have the power of life and death over them.

The word 'participant', which is more appropriate and is used by more enlightened journals, is usually reserved for the clinicians/researchers who 'subject' their patients to medical experimentation. How much more satisfying it would be for the researcher to enlist such people as collaborators in a shared endeavour to discover scientific truth. Such a change in mindset might bring great rewards. As Carl Rogers suggested almost 30 years ago, when discussing psychological studies:

Suppose we enlisted every 'subject' as an 'investigator!' Instead of the wise researcher measuring changes in his subjects, suppose he enlisted them all as co-researchers. There is now ample evidence that the so-called naïve subject is a figment of the imagination...<sup>5</sup>

Note Rogers' use of the slightly softer word 'enlist' rather than 'recruit', implying persuasion rather than coercion. It is now being suggested that it would be good to go further and consult consumers in designing trials, and even in setting research priorities. Then the 'patient' is no longer passive, but becomes an active member of the research team. So far we have no better word than 'consumer' to identify the role of the informed patient who has taken the trouble to learn about research methods and can contribute insight and personal experience to trial design, or even suggest new topics for research. Some such people have adopted the term 'patient advocate' to describe a slightly larger role than the merely personal and individual in such situations. One would expect patient advocates to have a constituency to which they would refer back and consult, so that the views

they expressed would represent a wide client base. Patient advocates would speak up for people who might have difficulty in speaking up for themselves. They might act in a supportive role alongside individuals seeking help in a specific personal situation *vis-à-vis* medical professionals, or in a wider forum, in the sense pioneered in the USA, where Project LEAD (an acronym for Leadership, Education & Advocacy Development) trains women with experience of breast cancer 'to serve as consumer advocates at every level of the research and policy process'. It is described as an 'innovative science program for breast cancer activists'.

### Informed consent

Not all clinicians take so-called 'informed consent' seriously. Some consider that fully informed consent is 'needlessly cruel',<sup>6</sup> and at least until recently many doctors have regularly entered competent patients in trials without obtaining such consent,<sup>7</sup> (and of course patients' 'competence' to give informed consent is judged by researchers, not consumers.) Whether we are talking about research or treatment in ordinary practice, reality is reflected in the common metamorphosis of the word 'consent' from noun to transitive verb, as in 'I consented the patient' (meaning 'I obtained consent from the patient'), though a good intransitive verb already exists (to consent to). But a patient who 'consents to' something, or not as the case may be, is thereby put in the driving seat, and the balance of power is shifted to a point of something like equipoise. Such use of words illustrates the traditional mindset of clinicians and researchers. Only by asking him or herself 'would I wish to undergo this treatment, or take part in this trial?' can she or he transform the 'subject' into a 'participant' with human attributes.

When people decide to withdraw from clinical trials – which they have a right to do without giving a reason – pejorative terms are often used to describe this: 'non compliance' or 'dropping out' implies bad behaviour by the participant,

whereas 'withdrawal' is a more neutral term. Worst of all are those who wish to remain in a trial (possibly because of fringe benefits such as more frequent monitoring) but are non compliant (that is, they don't take the tablets). Such deviants may be found out by means of unannounced blood or urine tests (warning of them may merely invite cheating).

### Conclusion

To conclude, we should take care in choosing the words to describe our activities: our choices reveal more about ourselves than we like to think. So, who are we? We have agreed to describe each other as follows: HG is a former editor, a counsellor, a breast cancer survivor, a user and consumer of health services; a patient advocate; a senior citizen; an amateur violinist; a mother (and so on). AH is a doctor, a clinical pharmacologist, a former editor, Emeritus Fellow of the UK Cochrane Centre; a patient with osteoarthritis who has had a knee replacement, of course a user and consumer of health services, a past participant in clinical trials, a patient advocate; a senior citizen; a cyclist; a grandfather (and so on).

We hope that you can now better explain who you are.

### References

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- 4 Burchfield RW ed. *The New Fowler's Modern English Usage*. Oxford: Clarendon Press, 1996: 151.
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