# HEALTH INFORMATION AND THE CONSUMER

Papers from a symposium
held on 30th November 1994

Edited by Jane Griffin

**Office of Health Economics**
12 Whitehall
London SW1A 2DY

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# Introduction

Jane Griffin

This book contains the proceedings of a conference held by the Office of Health on 30 November 1994, the Office of Health Economics held a conference entitled 'Health Information and the Consumer' chaired by Lord Peston. The idea for the conference developed out of the results of a survey conducted on behalf of the OHE by Milpro to ascertain where people obtained their health information and what impact it had on their lifestyles and attitudes to health matters. The survey and the subsequent Briefing *(Griffin, 1994)* raised a number of important issues about the role of health information, health professionals responsibilities and the needs of consumers. The papers presented at the conference and published in this book seek to address these issues.

The OHE survey was conducted over a period of three weeks in October 1993. In each of the three weeks of the survey nearly 400 men and women over the age of 15 were interviewed. The total sample size was 1,194. Interviewing was conducted on a face-to-face basis in the interviewee's home by a trained interviewer and quota controls were set on age, social class (AB, C1, C2 and DE), working status (unemployed, part-time, full-time and retired) and sex. All interviewees were asked details of the following: their usage of various sources of health information; the relative importance of the various sources; the influence of media coverage on their attitudes towards screening, purchases from pharmacists, visits to GPs and lifestyle; and satisfaction with the treatment or advice received from their GP. Answers to these questions were analysed according to age, sex, social class, marital status and regional health authority of residence.

In the first question all interviewees were asked to indicate which sources they used to obtain health information (Table 1). The survey identified three key sources of information: television, magazines and newspapers, and the GP. For all age groups the source of information considered to be of primary importance was that given by the GP (Table 2). Forty-eight per cent of the sample considered the GP to be the most important source of health information. In fact, over 80 per cent of respondents included information provided by the GP in the top five sources. Magazines and newspapers scored 16 per cent and television 13 per cent. The number of people from all age groups who considered television to be an importance source of health information is perhaps surprisingly low, given that in any month 99 per cent of the population will have watched some television. Information received from friends or relatives ranked highly among those aged 24 and under — 14 per cent. Only 8 per cent of the total sample, however, considered it to be the most important source of health information.

TABLE 1 **Question: From which of these sources, if any do you obtain your health information?**

| *Response (Age)* | *All* | *15-20* | *21-24* | *25-34* | *35-44* | *45-54* | *55-64* | *65+* |
|---|---|---|---|---|---|---|---|---|
| Number of respondents | 1994 | 132 | 78 | 229 | 203 | 169 | 148 | 234 |
| | | | | *Percentages* | | | | |
| **Magazines/Newspapers** | **39** | **44** | **44** | **39** | **47** | **48** | **33** | **26** |
| **TV** | **31** | **37** | **31** | **31** | **43** | **25** | **25** | **26** |
| Radio | 9 | 3 | 6 | 11 | 11 | 9 | 9 | 11 |
| Leaflets in GP waiting room | 14 | 20 | 15 | 16 | 18 | 14 | 9 | 10 |
| **GP** | **38** | **30** | **37** | **34** | **34** | **41** | **44** | **45** |
| Practice nurse/ health visitor/midwife | 7 | 2 | 13 | 11 | 7 | 7 | 7 | 6 |
| Pharmacist | 15 | 16 | 14 | 18 | 19 | 13 | 11 | 13 |
| Other health professional | 6 | 3 | 8 | 8 | 6 | 7 | 7 | 4 |
| Friends and relatives | 19 | 32 | 23 | 22 | 20 | 20 | 18 | 7 |

*Note:* Colums do not add up to 100 per cent as respondents were able to select more than one source of information.
*Source:* OHE.

TABLE 2 **All respondents most important source of health information ranked from 1 to 9 (1 being high)**

| *Source* | *All* | *15-20* | *21-24* | *25-34* | *35-44* | *45-54* | *55-64* | *65+* |
|---|---|---|---|---|---|---|---|---|
| Magazines/Newspapers | 2 | 4 | 2 | 2 | 2 | 2 | 2 | 3 |
| TV | 3 | 2 | 4 | 3 | 3 | 3 | 3 | 2 |
| Radio | 9 | 9 | 9 | 7 | 9 | 9 | 9 | 7 |
| Leaflets in GP waiting room | 7 | 8 | 5 | 7 | 4 | 7 | 8 | 5 |
| **GP** | **1** | **1** | **1** | **1** | **1** | **1** | **1** | **1** |
| Practice nurse/ health visitor/midwife | 5 | 6 | 5 | 4 | 5 | 4 | 5 | 8 |
| Pharmacist | 5 | 4 | 7 | 5 | 5 | 8 | 7 | 4 |
| Other health professional | 7 | 6 | 8 | 7 | 5 | 6 | 6 | 8 |
| Friends and relatives | 4 | 3 | 2 | 6 | 5 | 4 | 3 | 6 |

*Question:* Please can you rank these sources from 1 to 9 in order of importance to you in terms of where you obain health information.
*Source:* OHE.

Table 2 also shows the relative value placed on information given by pharmacists. The OHE survey found that fewer people ranked information supplied by pharmacists as either first or second most important source, compared to that supplied by the GP, the media or friends and relatives. This finding is supported by a recent study of consumer expectations of community pharmacists commissioned by the Department of Health *(DoH, 1991).* In this study although 66 per cent of consumers believed that it was the pharmacist's job to give general health informa-

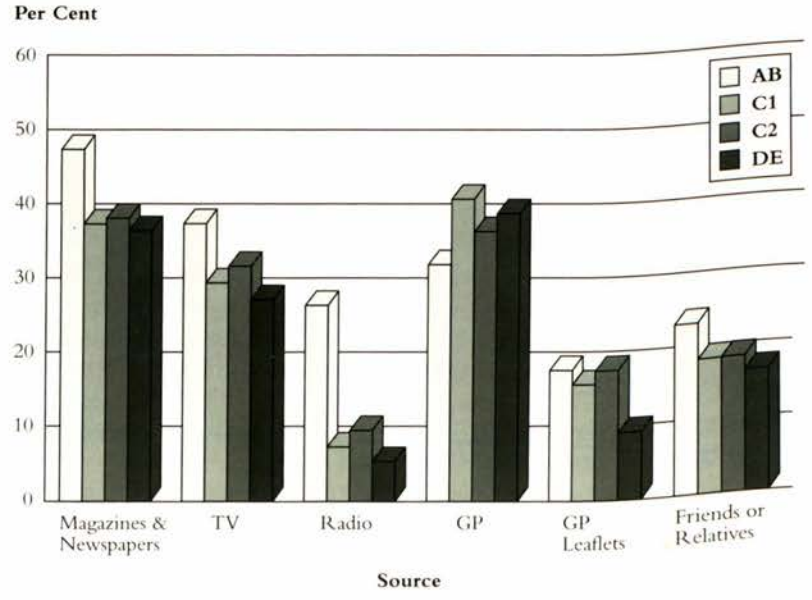
tion about minor ailments, only 45 per cent had ever sought advice from their pharmacist. Of those who had never asked the advice of a pharmacist the majority, 78 per cent, said that it was the doctor's job to give health advice and over half, 53 per cent, also said that pharmacists would not know enough about their health — clearly valuing the continuity of care offered by the GP.

Clearly, Pharmacists as information providers have some barriers to overcome in their relationship with the consumer. Four speakers — Dr Philip Brown, Mrs Linda Stone, Derek Prentice and Dr Felicity Smith, took part in a debate at the conference on the role of the pharmacist in the provision of health information and stimulated considerable discussion amongst the audience. Part of the discussion is reproduced in this book.

When the results from Table 1 were analysed by social class, our survey showed that people from all social groups used a variety of sources to obtain their health information.

However, members of social group AB are more likely to use a wider variety of sources of health information than members of C1, C2 or DE (Figure 1). This may mean that social group AB are more conscious of health issues, but it is interesting to note that a substantially higher proportion of members of social group AB obtain health information from newspapers and magazines than from their GP.

FIGURE 1 **Sources of health information by social class**




*Source:* OHE.

TABLE 3 **Question: How satisfied were you with the treatment and/or advice given by your GP?**

| *Response (Age)* | *15-20* | *21-24* | *25-34* | *35-44* | *45-54* | *55-64* | *65+* |
|---|---|---|---|---|---|---|---|
| *Men* | | *Percentages* | | | | | |
| **Very satisfied** | **23** | **56** | **45** | **53** | **55** | **56** | **71** |
| **Fairly satisfied** | **39** | **23** | **35** | **36** | **33** | **24** | **16** |
| Neither satisfied nor dissatisfied | 13 | 5 | 6 | 2 | 1 | 7 | 5 |
| Not satisfied | 16 | 17 | 9 | 7 | 3 | 6 | 5 |
| Don't know | 8 | – | 5 | 2 | 7 | 7 | 3 |
| *Women* | | | | | | | |
| **Very satisfied** | **46** | **57** | **42** | **57** | **67** | **68** | **61** |
| **Fairly satisfied** | **31** | **18** | **31** | **24** | **12** | **17** | **22** |
| Neither satisfied nor dissatisfied | 5 | 10 | 2 | 5 | 6 | 3 | 1 |
| Not satisfied | 15 | 11 | 25 | 11 | 10 | 12 | 12 |
| Don't know | 3 | 3 | 1 | 3 | 4 | – | 4 |

*Source:* OHE.

Whether this is because social groups AB have greater access to this kind of information, or whether it is a reflection of their lower GP consultation rates is open to debate. In fact all sources of written information included in the survey were considered to be more useful by social group AB.

Dr Sharon Gibbs in her paper discusses the results of her research into medicines and the use of patient information leaflets. Her work in this area demonstrates that patients want information about their medicines and value leaflets which have been written in an understandable fashion, but that the impact these leaflets have on the way patients take the medicines is questionable.

Linked to this issue is the result from another question asked in the OHE survey. Interviewees were asked the extent to which media coverage of health problems had affected their attitude towards screening services; eg blood pressure, cervical smears, screening for breast cancer, et cetera. Whilst it could not be argued that the media has an overwhelming impact in this area, the difference between social group AB and social group DE is not insignificant. Forty-two per cent of social group AB said that media coverage had made them more likely to have screening as opposed to 32 per cent of DEs.

There are two issues to be considered here. Firstly, to what extent consumer awareness of health issues is largely confined to social group AB and this is discussed by Rabbi Julia Neuberger in her paper. She addresses the rise of consumerism in health care and looks at the notion that patients' rights are a middle-class phenomenon.

The second issue to be raised is that if the media has limited impact on people's lifestyles and behaviour what impact does the GP have? The OHE survey results would seem to suggest, and other research would appear to back this up, that whilst the media fulfils an important role in providing information it is necessary for there to be a relationship between that information and the personal situation of the individual for there to be a change in behaviour. There needs to be an interactive process between the giver of information and the receiver. GP consultations are, by definition, interactive and provide an opportunity for educational dialogue and an exchange of ideas between doctor and patient.

Table 3 shows the responses for men and women to the question 'How satisfied were you with the treatment and/or advice given by your GP?' This refers to their last consultation. Overall, our survey found that 80 per cent of respondents were very or fairly satisfied with the treatment and/or advice provided by their GP. However, although 80 per cent does represent a high degree of satisfaction it is in fact a fall of 10 per cent in a little over ten years. When Cartwright and Anderson asked a similar question in the early 1980s the level of satisfaction was 90 per cent.

It is possible that this increased dissatisfaction in some way relates to the type of health problem they are presenting with. For example, in our survey the least satisfied group were women aged 25 to 34. Apart from the over-65s or young children, this is the group of people with the highest GP consultation rates. Alternatively it may be a reflection of increasing consumer awareness and the resulting loss of status for professional groups.

Whatever the reason, it is important to recognise that there is a clear relationship between satisfaction with a medical consultation and compliance with the advice given. Satisfied consumers are more likely to follow advice.

This being said, given the generally high level of satisfaction with their GP and the high value placed on the information they provide found in our survey, it might appear that the GP is well placed to influence patients' behaviour in terms of lifestyle and screening uptake. It is therefore disappointing to find that their impact may be limited, particularly amongst those social groups at highest risk, ie social groups C2 and DE. Dr Peter Toon in his paper discusses the results of his research into the effectiveness of GP-based health promotion programmes and the difficulties in targeting high-risk individuals.

It should be recognised that both GPs and pharmacists have to meet certain obligations in their relationships with consumers, and in her paper Diana Brahams considers the legal implications of providing health information to consumers.

Health workers often despair of getting the public to comply with health advice. It has been suggested that this is in part due to an over-reliance on brief doctor-patient consultations as the sole agent of change. But the doctor's recommendations are only one factor in health behaviour and unless the patient perceives the relevance to his/her life, immediate behavioural change is unlikely. Other factors which impinge on individual behaviour are social pressures which are more easily changed by public advertising and media campaigns. Major changes are taking place in health behaviour as a consequence of these social forces. Related to this, Noel Hall in his paper, presents and discusses the role the pharmaceutical industry can and should play in providing the public with health information.

One of the most detailed studies ever carried out on the health and lifestyle of the British population was carried out in 1984 and 1985 — HALS 1. It examined how people's behaviour and the circumstances in which they live affect their physical and mental health. Over 9,000 adults were questioned about major aspects of their lifestyle, including diet, exercise and smoking and alcohol consumption. They assessed their own state of health and reported past and present illnesses. Soon after, a nurse carried out physical measurements such as height, weight, blood pressure and lung function. The survey was repeated in 1991 and 1992. Of the original sample, over 5,000 were traced and re-surveyed. These two surveys show how people change over time. In the area of diet there are some particularly marked changes. It was found that over seven years there was a marked fall in the consumption of high-fat foods; butter and margarine had been largely replaced by polyunsaturated and low-fat spreads. It is interesting to note that whilst dietary changes are notoriously difficult to achieve, commercial interests, backed by advertising, have succeeded in massively increasing sales of butter substitutes by referring to supposed health advantages. The original message about polyunsaturated fats was a complicated one and yet it has been transmitted, and appears to have led to changes in a population's eating behaviour or at least what they purchase from the supermarket.

Modest increases in bran and fibre consumption and the reduction in the number of people taking sugar in their tea and coffee was also noted in HALS 2. These are examples of changes which go beyond mere food fads and which alter national patterns of consumption in a long term way.

What can be concluded from these findings is that health behaviour of the public can be changed by long-term sustained and extensive information campaigns which recruit people as participators in health-maintaining activities. Results do not occur immediately, nor do people always change as intended, but nevertheless changes do occur. However, media and government-backed public health campaigns only increase

awareness and help to formulate public opinion. To change an individual's lifestyle it is necessary for the individual to understand the health message and to accept the relevance for their own lives. The GP, in the role of health educator, is well placed to positively develop and build upon the lifestyle information which has been received by the patient from a variety of sources. Since health knowledge and lifestyle changes appear to occur over time, the continuity of care provided by the GP permits the monitoring of the patient's health and increases the effectiveness of health advice given.

To conclude, I think it would be difficult to better the words of *C M Fletcher* who, in the 1973 Rock Carling Lecture argued that:

> 'The purpose of information is not just to deliver a message, but to effect change in knowledge, attitude and eventually behaviour'.
>
> 'Communication must be matched to the knowledge, social background, interest, purposes and needs of the patient'.
>
> 'Words must have the same meaning for giver and receiver'.
>
> 'If communication is to change behaviour, the patient must see more advantages than drawbacks in the new behaviour'.
>
> 'Communication demands effort, thought, time and often money'.

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# Inverse care in the inner city — the targeting of GP health promotion resources

Dr Peter Toon

In this paper, I want to discuss some aspects of access and efficiency of health promotion work in general practice. Firstly, I would like to consider a small piece of research carried out by a group of young doctors training for general practice in Hackney in 1991 whose research I was supervising, which was published earlier this year *(Griffiths et al, 1994)*. This dealt with one aspect of health promotion in general practice — the new patient health check.

My training is as a behavioural scientist, so you will not be surprised to hear that I was carrying out this sort of work. What some of you may not know is that most of my academic effort has been devoted not to empirical science but medical philosophy. So, secondly, it is to a philosophical analysis of the assumptions underlying our prevention strategy raised by this study that I would like to turn.

Finally, I shall suggest the major challenge which this poses to our current prevention strategy in general practice and the issues which we need to tackle, which are particularly highlighted in our inner city areas, but are certainly not peculiar to them.

Let me start therefore by explaining the background to our study. Payment for new patient health checks was introduced in 1990 as one of a number of changes in the general practitioner's contract. Although one can only speculate on the thinking in the Department of Health which led to these changes, several aspects of patient registration were being discussed prior to this. First, turnover of patients has a considerable influence on general practitioner workload. Not only does the doctor have to get to know the patient and his or her medical history from scratch, which takes time and effort; people often only decide to register with a new doctor when they are ill. This means that a higher proportion of new patients than those previously registered will actually consult the doctor. When the overall list size is stable, this is to some extent offset by those who have moved away but not yet re-registered with a doctor elsewhere.

Another factor is that high mobility is associated with things such as mental illness and lack of social support, which tend to lead to high consultation rates. This is particularly important in inner city areas. For all these reasons, there was an argument for some sort of additional payment to doctors for newly-registered patients in order to reward doctors fairly for the additional work.

The payment which actually emerged, however, was not just an extra signing-on fee for a newly-registered patient, but a payment for performing a new patient health check, covering screening for various conditions and assessment of lifestyle risk factors, with appropriate health education. A strong general theme of the contract was prevention, and in particular the need to reach non-attenders. The results of surveys such as the OHE data *(Griffin, 1994)*, showing the importance of general practitioners as perceived authorities in lifestyle change and health education, was strong in the thinking of the Government at the time. Thus, for example, doctors were also required under the contract for the first time to invite all those who had not been seen in the last three years for a health check. Target payments were introduced for reaching defined levels of coverage for immunisation and for cervical cytology. The clearly laid out screening and health education agenda which was the requirement for the payment for the new patient health check, and which could be claimed for all newly registered patients, therefore seems to be another attempt to increase population coverage of individual health promotion activity. The mobility of some of the most vulnerable and hard-to-reach, which I have already mentioned, is in theory an attractive feature of this method.

A few months after this system had been introduced, however, it had become clear that although all new patients were invited to a health check not everyone took up the offer. My group of GP trainees had the impression that those who did attend were the 'worried well' rather than those at greatest risk of ill health, and wondered exactly what was being achieved by all this activity. The new patient health check took a doctor or a nurse about 20 minutes on average to do thoroughly, in addition to the administrative burden involved. The group decided to look at this as the research project which they undertook as part of their postgraduate training under my supervision.

They arranged for a questionnaire to be distributed by receptionists over a five-week period to all the patients registering at the seven practices where they worked. As well as basic demographic data, the questionnaire covered attitudes to smoking, alcohol, diet, exercise, weight and cervical smears. In such a short study it was impossible to demonstrate actual change in health-related behaviour, even if these had occurred. They therefore measured intention to change unhealthy aspects of lifestyle, on the not unreasonable assumption that unless one could demonstrate a change in intention it is unlikely that actual change would occur. It is important to bear in mind, however, that the converse does not necessary apply; intention to change may not lead to actual change.

At the same time as she gave out the questionnaire, the receptionist invited the patient to have a health check and a second questionnaire

was put in the patient's notes, to be given to him/her when they attended for their check. Because of the high proportion of Turkish patients in Hackney who do not speak English, a Turkish version of the questionnaire was also prepared.

The trainees also gave a separate questionnaire to the doctors and nurses actually carrying out the checks, to determine what topics they usually covered. This was a general questionnaire for each doctor and nurse and did not indicate what topics were covered with each individual patient.

Questionnaires were offered to 356 patients and completed by 255. Of these 118 attended a health check. This confirmed the impression we all had from the payment figures, that only about half the patients registering in Hackney practices attend their new patient health checks.

The questionnaires enabled us to compare the demographic profile of attenders and non-attenders. We found no differences in age, sex and educational level, but non-attenders were more likely to be of lower social class, unemployed, of African origin or to be heavy smokers. Amongst the women, non-attenders were less likely to have had a cervical smear in the last three years and were more likely to be single mothers.

Amongst those who attended the health checks, comparison of the two questionnaires enabled the trainee group to compare intention to change health-related behaviour before and after the health check. Motivation to reduce consumption increased amongst smokers and those who drank alcohol heavily. There was however no change demonstrated in motivation with respect to diet, exercise, excess weight or attendance for cervical smears.

Two conclusions thus emerge from this study. First, the trainees demonstrated that what is sometimes known as the inverse care law applies in this area, ie that those most in need of care are least likely to receive it. When a preventative service is offered, those most likely to take advantage of it are often the 'worried well' who have low risk but high anxiety about their health; whilst those at greatest risk are either so preoccupied by other concerns, such as where the next meal for the children is coming from or how to pay the gas bill, or so well defended by psychological defences of denial of their own vulnerability, that they cannot be reached. Thus, generalised campaigns may fail to make a significant impact on risk factors and hence on morbidity, but simultaneously have a negative effect on the quality of life of those who do take part by raising their anxiety.

Secondly, the impact of the health check even on those attending was limited. We did show some effect with respect to the fairly simple messages on smoking and alcohol, although whether these were translated into actual change in behaviour is unknown. Many studies have consid-

ered the problem of helping people to give up smoking and, although there is no simple answer, medical contact does seem to play a useful, albeit very limited part.

There are some other studies that suggest the situation with alcohol may be different. Many heavy drinkers mixing with other heavy drinkers appear not to realise that their behaviour is abnormal or harmful, and once they are encouraged to face up to that reality, change often follows without too much difficulty. Thus, for example, Southgate et al *(unpublished)* found that a decrease in heavy drinking was the one successful outcome of their men's health programme in Hertfordshire.

Despite the fact that in our study 79 per cent of doctors and nurses claimed to cover diet, exercise and weight loss in new patient health checks, we found no increase at all in intention to change as a result of these conversations.

In the light of these points, I now wish to consider in more general terms what our strategy for health promotion in primary care should be. The first task is to make some distinctions which often seem to become blurred in thinking about these issues.

The first distinction which it is helpful to make is between health education for lifestyle change on the one hand, and screening and immunisation on the other. Both are potentially important aspects of health promotion, but whereas in screening and immunisation the active partner is the nurse or doctor, with a comparatively passive patient who only has to be persuaded into the surgery or clinic, lifestyle change is primarily carried out by the patient. The role of the health profession is to encourage and advise; whilst this may be a necessary cause of change, it is far from being sufficient.

There is a continuity between the two. Patients have to be persuaded that attendance for immunisation or a screening procedure is worthwhile, just as they have to be persuaded to make a change in lifestyle. But the effort and cost involved in getting to the surgery every three years for a cervical smear and in going to the swimming pool or gym three times a week is of a very different magnitude. A different strategy may therefore be indicated in the two areas. The second distinction I want to make is between assessing risk, recording risk and reducing risk. I spent much of the 1980s working in coronary prevention and I lost count of the number of papers I read and presentations I heard on more and more sophisticated ways of predicting who would have a heart attack and how likely this event was. Whilst this may be a useful preliminary to intervention and important for targeting resources, assessing or recording risk per se has no effect whatsoever on health, unless we can actually change it.

When I say that, it sounds trite and almost self-evident, yet general practitioners are at this moment involved in a massive exercise under the

health promotion banding scheme which focuses on the recording of risk factors in medical notes — not so much because this is important but because it is measurable. Our strategy needs to focus on risk reduction as well as on assessment and recording.

It is unfortunate that the bulk of research on prevention in primary care has also concentrated on assessing risk and on developing systems to reach and to record risk data, rather than studying in detail ways to intervene successfully on which problems and with which individuals.

The third distinction I would like to make is between the provision of information and the alteration of behaviour. Much of our strategy about health education still seems to assume that the problem is ignorance and that if people knew what they should do and were advised to do it by a doctor or a nurse then they would do so. Sadly, this is not the case. A strategy based on such a rationalist approach is doomed to failure. The determinants of behaviour are complex and we need to understand them, not only in general but in relationship to particular individuals and risk factors, if we are to succeed in promoting change. Many people in health education have done a lot of work on this, but not all of this or indeed much of this has yet had any practical influence on practice.

The fourth distinction I want to make is between the magnitude of the risk and the magnitude of a change possible. Let me talk about this with a concrete example. As stated earlier, the results from our study and others suggest that whereas advising a heavy smoker to give up has a very low success rate, advising heavy drinkers to reduce their consumption may have a higher success rate. Here a significant proportion of people are able to decrease their intake to safe levels when advised to do so. There may be various reasons for this. Whatever the reason, if it is true that giving advice to those who drink excess alcohol is more likely to result in change in behaviour than advice to smokers, the change possible — what in fashionable jargon seems now to be referred to as 'health gain' — with heavy drinkers is greater than heavy smokers, even though smoking poses a greater threat to health than alcohol.

This distinction is of vital importance for one factor on which one might justifiably seek to base a health promotion strategy — the search for cost effectiveness. It is to the targeting of health resources that I now wish to turn. First to talk about cost effectiveness and then to talk about the related but rather different issue of justice.

At first sight it seems to make sense to target resources towards those who have the highest risk and towards the most important risks. But, as stated, unless they can be changed there is little to be achieved by targeting resources in this way. Effort expended on a lesser risk but one where greater change is possible may be more cost effective.

New patient health checks, like the health promotion banding sys-

tem, target payments and the contractual health promotional requirements, seem to be based on the belief that the effectiveness of a health promotion programme is best measured by how high a proportion of the population a procedure is carried out on.

This may be true for immunisations, where the patient is passive and the risk of exposure is as near as possible random, and if you immunise 90 per cent of the population you prevent at least 90 per cent of the risk. As our study suggested, however, for new patient health checks it is likely that for some procedures those at highest risk are the hardest to reach. This may also be true of some screening procedures, such as cervical cytology, where there is some suggestion that those most at risk are least likely to participate — the inverse care law again.

The cost of intervention, in time and other resources, also needs to be considered. A cheap intervention of low effectiveness may be cost effective. You will probably remember *Russell et al's (1979)* famous research in which the effect of GPs giving simple advice on stopping smoking was found to have a measurable, albeit low success rate and was calculated to be a cost-effective intervention. Equally, a more intensive intervention, if it can be properly targeted on a selected group with a high probability of success, may be a more cost effective use of resources.

A cost effective model should take account of quality as well as quantity. Not only should we consider the nature of the intervention offered, we will also consider how they are targeted on those who can and wish to make a change. This may involve us in a sort of triage: ignoring those at low risk and a much harder writing-off of some at high risk as unreachable, focusing on a group where the potential for success is highest.

Like all medical interventions, we have to bear in mind that health education carries potential risks as well as benefits. These are often overlooked, but some recent studies have suggested that health checks can sometimes do more harm than good, by producing fear of illness and increasing anxiety. As with any medical procedure, we need to consider how to reduce the risk of this harm to maximise potential benefits and to balance the trade-off between the two.

The other issue which one needs to consider in formulating a health promotion strategy is justice. Just distribution of a resource may be based on a variety of factors appropriate in different situations. Sometimes it is just to reward people according to what they deserve, as in just punishment; sometimes according to merit, as in the awarding of university degrees; or what they have been promised, or to what they are entitled, as in contractual disputes; sometimes according to their needs.

To offer everyone the same is not necessarily just, neither is it the same as treating them equally. All the patients in our study were made the same offer of a new patient health check. One might argue that the

decision of some of them to take up the offer and others not was a free personal choice, and so all had been treated equally. The counter argument, however, is to question whether a single parent with many other pressures and concerns, who has to use public transport and bring her children to the surgery, is as free to take up that offer as someone who has his own transport and can control his own timetable. A strategy based on offering the same to everyone may no more be just than it is cost effective.

It is not easy to say what a just prevention strategy would look like. Clearly the operation of the inverse care law suggests that simply treating everyone the same is not at all the same as treating everyone equally. We need to make a clear and political decision to what extent we feel it is appropriate to make deliberate attempts to correct this balance by targeting resources on the most disadvantaged with the highest needs, and how to do this.

I do not have time here to develop a detailed theory of just allocation of health promotion resources, but it is clear to me that we have to face up to the need to develop such a theory. We also have to recognise the unpalatable fact that a strategy based on cost effectiveness, measured in terms of reduction in risk factors, as I have discussed previously, will not necessarily be the same as a strategy based on maximum justice. This is another hard choice we will have to make.

What then should we do about prevention in primary care? Although I have not provided any solutions, I think the issues which we have to address are becoming clearer. We need a model of health education based on a sophisticated understanding of the complexity of health promotion, with its different aspects and health-related behaviour, not merely on simple agendas — treating immunisation, screening and health education as if they were the same, and as if health education were merely a matter of transmitting information.

We need a model to set priorities, which takes into account not merely risk assessment but assessment of the potential for change, the magnitude of the obstacles facing us and the magnitude of the resources needed to achieve that change. Health promotion, like politics, is to a considerable degree the art of the possible. The agenda has in general been set on the basis of the importance of risk factors rather than their susceptibility to change. This is misguided.

Finally, we need a strategy which has addressed the real and difficult issues of the inequality of access to health care which exist in our society and which take justice as well as cost effectiveness seriously. Our present approach is not the best strategy according to either criteria.

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# The implications of marketing medicinal products to consumers

Noel Hall

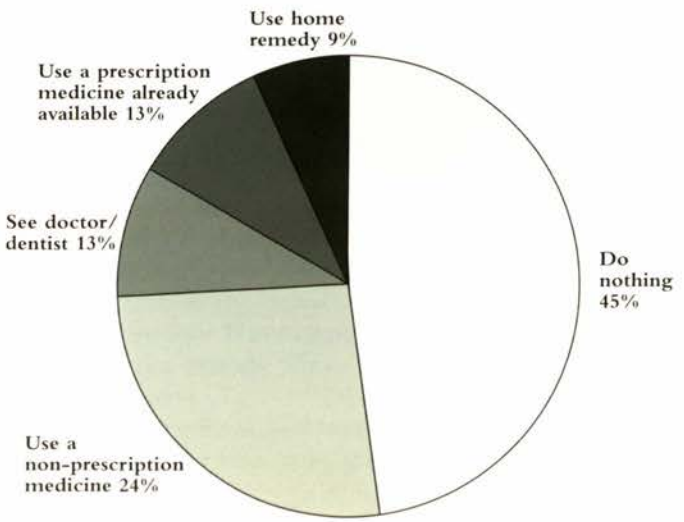
This paper focuses predominantly on pharmacy (P) medicines. In recent years, the public's use of P medicines has increased dramatically, the current market is estimated at over £1,000 million. More and more products are being switched from prescription only medicine (POM) status to P medicine status and last year 14 products made this change, which is more than double the total of the previous decade.

The Health of the Nation and the Patients' Charter initiatives are encouraging consumers to take greater responsibility for their own health. It appears, therefore, that POM to P switches are good news — not just for the industry, but for consumers, Government and pharmacists.

**What the consumers think**

In the 1980s, the Proprietary Association of Great Britain carried out some research into how consumers feel about self-medication and what steps they take to treat ill-health. It should be noted that 95 per cent of the consumers in this survey had a typically cautious attitude towards the use of medicines, Figure 1 shows that 45 per cent do nothing at all about their ill health. While about 75 per cent of consumers thought it was

FIGURE 1 **What do people do about ill health?**



important that P medicines should be made available for minor illnesses, they also felt that they should only be used when absolutely necessary.

Some surprising information came out of this survey.

- many consumers felt that frequent use of a medicine might diminish its efficacy.
- 36 per cent of the sample believed that only medicines prescribed by a GP could provide help for their particular ailment.

**Several factors are driving the trend towards self-medication**

Governments world-wide are committed to reducing their medicines bill. Switching products from POM to P status may enable them to achieve this. It has also been suggested that making more products available over the counter (OTC) may free up GPs' time, although for GPs working in inner city areas, where many patients receive free prescriptions, this is unlikely to be the case.

For pharmacists, moves to make more medicines available OTC provide business opportunities that they need to exploit.

The pharmaceutical industry is looking for creative ways to overcome patent expiry on their existing prescription-only medicine brands. Switching a product to a P status may enable them to achieve this goal.

Consumers may welcome the availability of medicines over the counter, in many cases visiting the pharmacy provides consumers quicker access to a health care professional compared with making, and waiting for, an appointment with their GP.

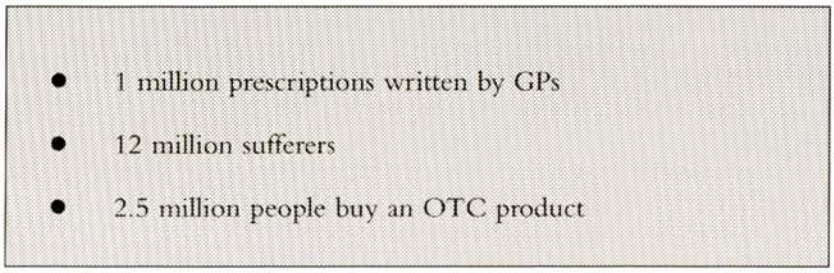
**Issues for manufacturers to consider**

There are four main issues which manufacturers should recognise if they are going to successfully market a P medicine:

- Consumers need knowledge in order to self-medicate appropriately. They need to have sufficient understanding of their symptoms to enable them either to choose a medication themselves or explain their needs clearly to their pharmacist.
- Many consumers are resistant to the use of medicines.
- Consumers do not currently view pharmacists as an important source of health advice.
- Some concerns have been expressed by the Consumers Association over the potential misuse of those more powerful medicines that have switched to P status. In particular, there is some concern that use of P medicines may result in the masking of a more serious underlying illness.

To market a P medicine successfully, the manufacturer must persuade the consumer to do three things: self-diagnose; identify an appropriate medicine; use the medicine effectively.

FIGURE 2 **The cold sore market**




**Case history — switching Zovirax cold sore cream (Wellcome) from POM to P**

When Wellcome were making the decision to switch, a number of factors were considered.

- The vast majority of people getting cold sores were visiting their GP once the sores had already developed. However, clinical trial work carried out ten years earlier had shown that the product is best used during the 'prodromal' phase, when the person is aware that they have a cold sore 'coming on'. Therefore, the time taken waiting for an appointment with the GP presented a problem in terms of the best therapeutic use of the medication.
- Safety is the prime concern of the Medicines Control Agency (MCA) when reviewing an application for a product to be switched OTC. Zovirax, in its many different forms, had an excellent safety profile. The incidence of adverse drug reaction was 0.01 per cent, this is extremely low, and there was extremely high patient exposure.
- Cold sores are a condition which can be easily self-diagnosed. Furthermore, research with pharmacists showed that they were confident about helping consumers to make a diagnosis.
- For a manufacturer, it is important to have early discussions with the appropriate medical specialists who may have fears and concerns about a medicine that they know and use every day being made available directly to the consumer. In the case of Zovirax, concern was expressed that resistance might develop to the drug. It was important therefore to persuade virologists that this would not be an issue. Furthermore, since Zovirax is used to treat life-threatening herpes infections in neonatal units it was necessary to allay any fears that the paediatricians in those units might have had.

Figure 2 shows the cold sore market in the UK before the switch of Zovirax Cold Sore Cream from POM to P. There were 1 million prescriptions written by GPs for Zovirax in the treatment of cold sores and epidemiological studies had shown that there were about 12 million sufferers in the UK. It was known that about 2.5 million people in Britain

would go into a pharmacy shop and buy an OTC product of some description. It was also understood that about 3.5 million people used a variety of home remedies to treat cold sores. There was also a significant number of people who did nothing about cold sores. In order to be successful with Zovirax it was necessary to persuade the non-treater to treat.

**Consumer concerns**

It is particularly important for a manufacturer that is predominantly ethically based — ie predominantly involved in the marketing of prescription-only medicines — to be aware that when they switch a product the customer is no longer a health care professional but a consumer.

Running consumer focus groups provided Wellcome with a great deal of information about how consumers view their cold sores, what their reasons were for using products already on the market and what their attitude was to the concept of Zovirax. The unique selling point of Zovirax is its ability to prevent a cold sore from developing and, unsurprisingly, the research showed that it was this quality that the groups considered to be the most significant benefit of the product.

**What stops people self-medicating?**

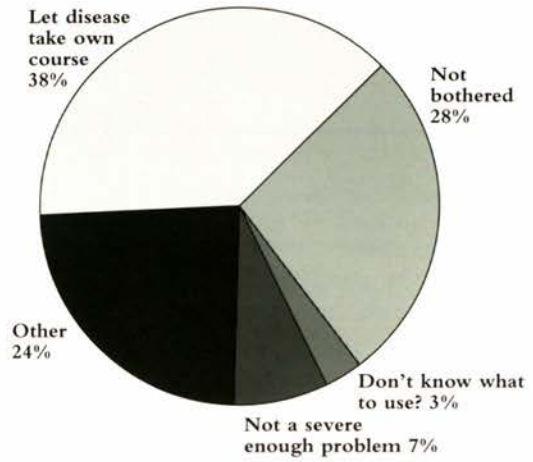
Figure 3 shows some of the reasons that were given for those consumers who did nothing about their cold sores and what would persuade them to treat. Thirty-eight per cent of participants said that they did not treat because the cold sore 'took its own course' and 28 per cent said that they did not treat because the cold sore did not bother them. When asked what would prompt them to buy a product to treat a cold sore the majority, 46 per cent, said 'because it had been recommended'. It was important to be conscious of this work when conducting the programme to try and persuade non-treaters to treat. The research with focus groups suggested that the product should be positioned somewhere in between a health and beauty product. Some of the prescription heritage positioning options that Wellcome went through will be discussed later in the paper.

**Prevention and cure**

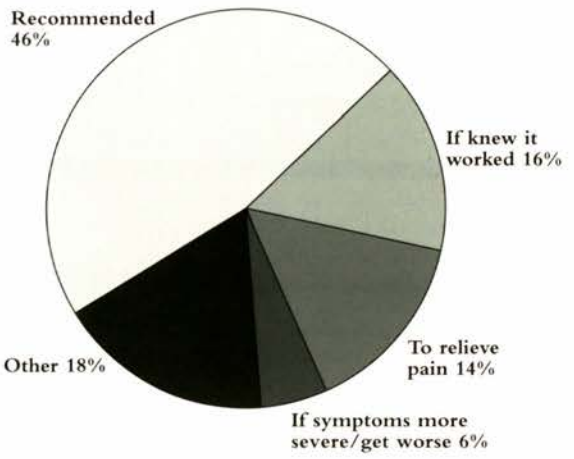
Many consumers found it difficult to understand the concept of prevention. Never before had they been faced with a product that could prevent their cold sores from developing. If for example, they were a Blisteeze user, they were used to rubbing some cream on their cold sore as a palliative to stop their lips from cracking.

The research revealed that most sufferers recognised when they were getting a cold sore — they felt run down, some people developed them when they went skiing, others when they were having a beach holiday.

FIGURE 3 **Reasons for not treating**




**Factors which would prompt non-treaters to buy a product**




Some people were experiencing warning signs and during the consumer focus groups, several consumers starting to use the phrase 'tingle' — 'I have a tingle in my lip and that is how I know I have a cold sore coming'.

## The right image

The choice of image for Zovirax was therefore paramount. It was found that sufferers who had eight to eleven attacks a year — the very severe end of the market — were attracted to the prescription heritage, by the

30 million patient exposures, and by the fact that this product, that had formerly only been available on prescription, could now be purchased from the pharmacist.

Some consumers who had only one, two or three cold sores a year, however, felt that Zovirax was a 'sledgehammer to crack a nut'. It is important, therefore, when switching a prescription-only medicine to address any concerns about the availability of very powerful medicines that may not be appropriate for more minor ailments.

**Treat the tingle**

Communicating the message that the product is best used early on, during the warning phase, was solved with a simple line: 'You should treat the tingle'. The aim of the campaign was to educate the consumer to be prepared — to identify the things that commonly triggered their cold sores and have Zovirax ready to hand so they could take it as soon as the warning signs appeared.

**Target audience**

Identifying the target audience for Zovirax in communication terms was quite straightforward. There was a significant bias towards women. Seventy per cent of all OTC products are purchased by women, who also tend to buy for men.

**Educating the pharmacists**

Since pharmacists were going to play a major role, giving advice and helping consumers to make a diagnosis, an extensive education programme was implemented before the product was launched. In the ten weeks coming up to the launch all pharmacists in the country received both educational material and information about Zovirax. A video on Zovirax which pharmacists could show to pharmacy assistants was also distributed. Pharmacy evening meetings were held and over 6,000 pharmacists attended. The relevant journals were sent educational material about the product which they then published. Through these different activities it was possible to ensure that pharmacists were informed and confident about discussing the use of Zovirax with consumers.

**Campaign style**

Every single element of the communications mix was used for the launch, which was extremely high profile. Experts discussed cold sores on the radio, talking, for example, about trigger factors and preventive measures. To make sure that there was wide-spread familiarity with the fact that Zovirax was now available over the counter, all the women's

magazines were targeted as were all health correspondents. On the day of the launch the Daily Mail carried the story, as well as two other national newspapers. There were reader offers in magazines and an information line on cold sores was set up. Every single area of the marketing mix was covered and every possible effort made to expose consumers to the message that this product was now available and that they should be ready to use it before they developed a cold sore.

**Importance of TV**

The importance of appropriate television advertising in persuading consumers to change their attitude should be emphasised. Before embarking on a major television advertising campaign a manufacturer needs to be certain that the desired results will be achieved.

Before going national, the advertising for Zovirax was piloted in three TV regions. All other elements of the promotional mix remained the same. Using the Boots EPOS (Electronic Point Of Sale) data, it was possible to track consumer purchases directly. In the regions in which the product was advertised, there were twice as many purchases of Zovirax compared with areas in which there was no advertising. TV therefore clearly had a significant impact in persuading consumers to purchase the product.

**Results**

Taking into consideration the circulation of the magazines and newspapers which covered the launch, over 15 million readers were exposed to messages about Zovirax Cold Sore Cream.

Unsurprisingly, there was a reduction in NHS prescriptions. Fewer prescriptions are now being written for the product than there were before the switch from POM to P medicine and there has been a significant expansion in the OTC market. Over 3 million people now regularly purchase Zovirax from their pharmacists. The share of the trade purchase by volume in one month was extremely high. The advertising campaign reached 46 million people in this country. When analysing how consumers were purchasing the product, it was interesting to note that 66 per cent of pharmacists reported that consumers were asking for Zovirax directly. A quarter of sales resulted from recommendation. Studies show that the awareness of both the Zovirax brand name and its visual image is extremely high.

Some recent research has examined whether consumers are using the product properly. It was found that three-quarters of all consumers are now purchasing Zovirax before they develop a cold sore and 96 per cent of consumers who use the product before they have a cold sore say that it actually prevents it. While this is not a clinical trial, it does show that consumers are happy with Zovirax and are using it properly.

**Hitches**

A couple of problems came up during the campaign. The Lawrence McGinty ITN survey, carried out in November/December 1993, looked at whether pharmacists were carrying out the supervisory role that would be required of them with the new POM to P switches.

As a measure of how well pharmacists were fulfilling this function, ITN researchers looked at whether pharmacists were pointing out to consumers that the product could not be used for the treatment of genital herpes. If the pharmacist did not make that recommendation they would score negatively and in this survey this is what happened in most cases.

It is worth questioning whether the provision, or not, of this particular piece of information is a suitable determinant of the pharmacists' expertise. It would perhaps be surprising if, in a busy pharmacy, someone walked in, said 'I get cold sores very regularly, may I have Zovirax' and was told by the pharmacist 'You cannot use it for genital herpes'. Wellcome was, therefore, not surprised that the survey gave the results it did. There was, unfortunately, some concern in the public about whether pharmacists were equipped to counsel consumers about cold sores. At the time the then President of the Royal Pharmaceutical Society, Mr Nicholas Wood, said 'I am alarmed to hear yet again of a survey claiming to show that pharmacists do not do their job properly — even though the (ITN) survey may be flawed it seems to show that a section of the membership needs to wake up to what is now expected'. Pharmacists confirmed, however, that the educational materials Wellcome had prepared were of an extremely high standard.

**Handling language for consumers**

Writing text for the P medicine indication sheet about the treatment of cold sores presents few difficulties. However, when dealing for example with H2 antagonists and phrases like 'hyperacidity' and 'dyspepsia' any manufacturer who is going to advertise on television, has then to go through the Advertising Clearing Council. The council checks that the claims the manufacturers are making are allowable within the framework of the P licence.

Some pharmacists have reported that consumers sometimes ask to use H2 antagonists to treat symptoms for which they are clearly not indicated. It is quite possible that people do not understand what hyperacidity and dyspepsia are. There is a need for the MCA to consider simplifying the language that is used, so that manufacturers are able to communicate their message in a more understandable way.

**Lessons and aims**

There is a danger of mollycoddling consumers, most of whom fre-

quently buy potentially dangerous products, such as DIY equipment, and use it intelligently and safely. Those P medicines where advice on usage is not necessarily essential should be identified, and made available as a GS (general sale) in supermarkets.

Secondly, the industry needs to make sure that pharmacists are equipped to carry out their new diagnostic and counselling role and that consumers are happy with this. To be successful with POM to P medicines it is necessary to research thoroughly, educate extensively, advertise widely, and focus on the consumer as the customer, realising that the consumer is completely different from the GP.

Thirdly, the pharmacy profession should carry out a major public relations and advertising campaign to explain its role to consumers. Consultation areas should be developed and disease management protocols implemented for those products which have been switched, so that there is an agreed common practice. Pharmacy undergraduate and postgraduate training could perhaps be changed to reflect this new role. It might be worth considering keeping patient medication record cards, so that consumers can feel confident that there will be no interactions with any of the prescription medicines they are taking.

Finally, consumers need to change their attitudes to the pharmacist. They need to know what questions to ask of the pharmacist. They need to know what medicines they are already taking. They need to take responsibility for reading all the relevant health information, including all the pack information. They need to be open-minded because their GPs may not always give them a prescription and that they may be advised to go and buy an OTC product. Finally, they need to know what to do if their OTC medicine is not working.

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# Medicines and the role of patient information leaflets

Dr Sharon Gibbs

What information do consumers get about their medicines? Traditionally, in the UK very little. Patients are often kept in the dark about the medicines they are prescribed. Studies have shown again and again that doctors do not give much information about medicines during consultations. Time pressure; patients who do not ask questions; and patients who forget what they have been told contribute to communication problems. These problems have led some to believe that written information about medicines would be an excellent back-up.

Unfortunately, the prescription medicine label does not give very much information to the patient. Prescription medicines were for a long time not required to provide very much in the way of helpful information at all. In fact 'The Tablets' was what used to appear. The name of the medicine has only comparatively recently started to appear on containers. All this is changing now. Labels on medicines, particularly those bought over-the-counter at the pharmacy, provide more information. Doctors and pharmacists are being taught communication skills as part of their training.

What other information sources are now available? There is a whole range. Books and lay pharmacopoeia are available for all; magazines and newspapers regularly cover information about medicines; TV documentaries; leaflets at pharmacies and doctors' surgeries are now available; leaflets about diseases produced by self-help groups often cover treatment options, side effects, et cetera.

But by far the biggest change is the recent introduction of patient information leaflets which will be provided in the pack with all medicines.

Council directive 92/27/EEC on the labelling of medicinal products for human use and on package leaflets is the directive that has made it all happen. From January 1994 'patient user leaflets', as they are termed, are being phased in with all medicines, unless all the information that is required can fit on the label. In reality this is unlikely, as a lot of information is required. It means that almost all medicines — whether they are prescribed or over-the-counter — must have leaflets and this leaflet will be in the pack with the medicine. This is the first time that manufacturers in the UK have been required to provide such information.

However, it is not the first time that they have produced leaflets. In line with ABPI guidelines, published in 1988, some manufacturers have been producing patient information leaflets on a voluntary basis. We are

talking about prescribed medicines here. Before that, only a handful of medicines came with manufacturers' leaflets. Unfortunately, those leaflets were either extremely technical, such as the oral contraceptive pill insert which was criticised for requiring a high reading age, or too simplistic such as instructive leaflets for eye drops or inhalers - sometimes excellent at telling people how to use the product, but not very good at giving information about risks and benefits.

I should like briefly to outline what will be in the new leaflets. The first thing that will be required is identification of the medicine. That means its name, all the ingredients, active and inactive, the form the medicine comes in, how much of the drug is in each tablet, the therapeutic group to which it belongs, and the name of the product licence-holder.

Secondly, indications for use must be stated. Contra-indications, precautions, interactions and any special warnings that might be necessary will also be listed.

The leaflets will contain instructions for proper use. This should include dosage, method and frequency of administration, duration of treatment, what to do in case of overdose, what to do if a dose is missed, and any risk of withdrawal effects if they exist. Side effects in normal use and what to do if they occur must be listed.

Storage precautions such as a warning not to use after an expiry date on the label; any special storage instructions, and warning against visible signs of deterioration will also be required. Finally, the date the leaflet was revised must be there. Clearly, quite comprehensive information is required.

Crucially for consumers the legislation makes it absolutely clear that this information is for them and for no one else. The leaflets must be written in easy-to-understand language and be presented in a way that aids communication.

However, there is a slight problem with this at the moment, because the guidelines on how this should be done are still in preparation somewhere in Brussels. What exactly makes an understandable, clearly-presented leaflet is therefore open to interpretation.

In considering what effects we can expect from the introduction of these patient information leaflets, I would like to examine several possible outcomes, including the effects these leaflets might have on consumer knowledge about their medicines, on their medicine-taking behaviour, on consumer satisfaction and on communication between doctors and their patients, pharmacists and consumers, and patients and pharmaceutical companies.

What do people know about their medicines? Not very much. Patients have been found to know very little — particularly about prescribed medicines. In a postal survey conducted 10 years ago in the

Southampton community it was found that respondents knew comparatively little about their medicines and that knowledge of side effects was particularly poor, with only 27 per cent being aware of any side effects associated with their treatment (Ridout et al, 1986).

Further studies (Gibbs et al, 1989a; Gibbs et al, 1989b) from Southampton involved the design and testing of patient information leaflets for six commonly prescribed therapeutic groups of medicines. In all over 1,600 patients were interviewed in their homes, using semi-structured questionnaires. Some of the patients received leaflets and others did not.

It was found that patients who received leaflets were better informed about every item of knowledge tested, except for the name of the medicine. The biggest improvements were seen in knowledge about the side effects.

However, there is some recent evidence to suggest that current leaflets may not be quite as effective in raising consumer awareness about their medicines as the ones used in the Southampton studies. Professor George (Sullivan and George, in preparation) has repeated his postal survey of the Southampton community. This time round, many of the respondents said they had received a leaflet — two-thirds of the people taking a prescribed medicine had received one. Surprisingly, this did not seem to have any bearing on their knowledge of side effects when they were asked about them. Only 30 per cent knew of any side effects — almost the same figure as 10 years previously, when there were no leaflets available at all. One could speculate on several possible reasons for this. But the one I would like to draw your attention to is the often complicated way the side effect information is being expressed in the leaflets. Does this confuse patients?

What about taking the medicine? In the Southampton studies we found our leaflets had no measurable effect on compliance (Gibbs et al, 1989a; 1989b). By 'compliance' I mean taking the medicine correctly, as directed. People often find this result difficult to believe. I think that is because the reasons for non-compliance are thought to be quite simple: either ignorance — people not doing what they are told because they do not know how to follow instructions; or to be downright disobedience, where people deliberately disobey doctors' orders.

I believe it is not quite as simple as that. There are many factors which influence 'compliance behaviour' — previous experience of the medicine or of the disease; what the patient knows about the medicine already; what the patient believes about the medicine and the disease (which is slightly different from knowledge); information provided by the doctor and the pharmacist; and crucially — what family or friends think about the situation; books, magazines, et cetera. It is far too simplistic to expect a leaflet to have a major impact on a complicated behav-

iour like medicine-taking.

Having said that, there is some evidence that people will alter their behaviour if they believe they have been given a medicine for a trivial reason. In the Southampton studies (Gibbs et al, 1989a; Gibbs, 1990), a handful of patients who had been prescribed non-steroidal anti-inflammatory drugs (frequently used for arthritis), decided to stop the treatment when they read a leaflet. When we looked back to see what they had been given the tablets for, it seemed that they had made a rational choice. The empowered consumer had decided not to take the tablets — and we could not fault their decision.

One of the biggest effects leaflets seem to have is on consumer satisfaction. In the Southampton studies (Gibbs et al, 1989a; 1989b), significantly more patients who received leaflets were satisfied than those who did not get them. I have heard this described as 'the cuddle factor'. I think it is a bit more than that. People are satisfied because they want this information. Again and again, studies have shown this. Almost everyone in the Southampton studies wanted leaflets.

Will people read these leaflets? Research from Southampton (Gibbs et al, 1989a; 1989b) suggests that they will. Almost everyone who got a leaflet read it, and thought it was a good idea to have one. I should point out that this research was conducted under slightly different circumstances, in that our leaflets were given out by the doctors at the GP's surgery, or by pharmacists when they were giving out a prescription. The new leaflets will arrive unannounced inside the pack with the medicine.

When we are talking about medicines that switch from POM to P, the leaflet may well be the only information the patient will receive about their medicine, making it much more likely that they will read this information.

Moving on, I should like to consider some of the problems associated with patient information leaflets and the factors which might limit their usefulness.

Questions which need addressing are; do the leaflets give the right amount of information, and how do we know? How will leaflets address the problem of poor readers? Will the information in leaflets be presented in a way which helps the consumer? Leaflets will be inside the pack so how will consumers be able to make informed choices about medicines if they cannot get the information before they buy or collect them? Finally, when will these leaflets be available with all medicines?

To deal with the first point, when we asked people in Southampton how much information they wanted, around half wanted short summarised points, just telling them the basics. The other half wanted more detailed information (Gibbs et al, 1987). So we tried to provide both types of information in our leaflets. We also tried to cater for those who

wanted even more information by giving a reference to a lay pharmacopoeia at the bottom of the leaflet.

The new legislation requires the leaflets to give a great deal of information. From a consumer point of view, this must be good news. It is high time that people had more information about their medicines. But a question mark remains as to whether some consumers will suffer information overload, especially if long lists of side effects creep in to satisfy lawyers.

My next question was about poor readers. How will the leaflets address the problem of poor readers? The Medicines Control Agency (MCA) has the task of making sure leaflets comply with the regulations. The MCA has produced guidance to the pharmaceutical industry which says that the language used should be simple without being patronising (MCA, 1993). They recommend that leaflets should be pitched at the level of difficulty found in tabloid newspapers. Fair enough, but who will be the judge of this readability? [As an aside here, we are not just dealing with poor readers; we should remember that the illiterate, the blind and those who cannot speak English will be excluded altogether from this information and should be given it elsewhere.]

Translating technical medical terms into lay language is not always easy. The following are some of the suggested translations made in the MCA guidance. Insomnia, 'difficulty sleeping'. I do not think many would argue with that. I guess most of us would say the second example was fair enough too — malaise, 'feeling unwell'. But the third? Arrhythmia does mean palpitations, but are we sure 'palpitations' is a term widely understood by the lay public? The MCA does not think it is necessary to translate words like 'nausea' and 'gout'. How do we know these are widely understood? It is not very clear to me that we know that. The only way to find out whether people really understand the terms used in the leaflet, within the context of the leaflet itself, is to test the whole leaflet on the intended audience.

Another issue which will influence readability is the way information is laid out and graphically presented. Things like type size become extremely important when sight is failing, as is often the case with elderly medicine-takers. Guidelines on this topic are taking a very long time to come out of Brussels. In the meantime, pharmaceutical companies are having to struggle on (with various levels of success), hoping to achieve the goal which has been set for them of readable, understandable but full information.

One of the other problems is that consumers will not see the leaflet until they unpack the medicine. This makes it difficult for the consumer to make informed choices about medicines before they buy the products or collect them. This is particularly important when medicines are bought over the counter. However, the detailed labelling of OTC prod-

ucts we are used to in this country goes a long way to alleviate this problem.

Consumers who have been prescribed a medicine by their doctor can always look up the ABPI patient compendium (1995-96), provided it is accessible and someone tells them about it. Personally, I doubt whether that will happen.

My last point relates to availability. The impact of the leaflets may be limited because of the way they are being phased in. Leaflets are required to be produced when licences come up for renewal. This could mean that consumers may have to wait until the end of the decade for some leaflets to be introduced.

Patient information leaflets on medicines have arrived. There is no going back, and that has to be good news for the consumer. Research suggests that improvements in knowledge and in satisfaction should follow, but there is unlikely to be improved compliance. To be beneficial the new leaflets must provide information in a way that consumers can use. The best way to find out whether consumers can use them is to ask.

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# The legal implications of the provision of health information

Diana Brahams

Whilst I write for *The Lancet on Medicine and the Law* and I edit the *Medico-Legal Journal,* I spend 90 per cent of my professional working time in active practice. I act for plaintiffs with claims for personal injuries: at a guess, (and disregarding multi-party actions), about 70 per cent of my practice is quite specialised dealing with claims for medical negligence; the rest of my case load is made up of general personal injury work due mainly to accidents at work or on the roads, in the home or injuries resulting from working conditions as well as injuries caused by defective products — and pharmaceutical products in particular.

I have been involved in multiple plaintiff litigation and large numbers of sets of papers have come through my hands all claiming for adverse effects from the same or a similar type of drug or product such as benzodiazepines, when there were some 16,000 legal aid certificates issued, I have also been instructed in the Myodil action.

I think I am well placed to assess what kinds of lack of information and adverse consequences bring clients to me to pursue claims for compensation against manufacturers, doctors (both GPs and hospital doctors) and against pharmacists, dentists and all manner of other professionals. As a result of this background of experience I probably perceive things from a different angle from most of those present at the conference.

The first thing I would like you to keep in mind is this: there are two legal types of constraints which *inter alia* regulate the supply of medicines and medical treatment to patients. Contract and tort. They may run in parallel but do not always do so, by any means.

Most people in the UK are treated under the NHS and thus, leaving aside OTC medicines, most of our medicines are supplied through the NHS prescribed by NHS doctors whose terms of service or conditions of employment are contained in NHS contracts. General practitioners are not employees, unlike their hospital colleagues. They are independent contractors for services with the Family Health Service Authorities (FHSA). Uniform style contracts for services have been negotiated on their behalf so contracts are not individually tailored for each GP's wants or wishes. However, please note, that these contracts are for the benefit of the GPs and their NHS patients but are not made between the GPs and their patients but between the FHSAs and the GPs.

It is also worth noting that there have been some radical changes built

into the new GP contracts. The new contract introduces an express term, for the first time, which requires positively that the doctor advise patients on how to achieve a healthy — or more healthy — lifestyle. There are some very specific and interesting requirements laid out.

As this contract is made between the doctor and the FHSA and not between the NHS GP and his NHS patient so the NHS patient has no direct contract with his GP or with any NHS doctor when that doctor provides NHS services. However, there is nothing to stop the doctor and patient from entering into a private contract whereby the doctor provides medical treatment in exchange for fees. Regardless of whether or not this happens, the doctor owes the patient a duty of care and he must treat the patient in accordance with responsible medical practice to avoid being liable in negligence. Under his new GP contract with the FHSA, however, the GP is positively required to do, I suspect, rather more than he would have thought necessary say, five years ago. If the doctor fails to carry out the terms of his contract he can be sanctioned in a number of ways. If his breach is very serious he can be struck off by the General Medical Council (GMC) and/or he may lose his contract with the FHSA, or he can have part of his remuneration under the contract docked by the FHSA if the patient successfully brings a complaint against him.

The disciplining of the doctor by the GMC and/or the FHSA will point to the fact that he has failed to act in accordance with responsible medical practice prevailing at the time of the incident complained of. However, responsible medical practice in any particular field is not engraved in stone but is constantly evolving. Practices change. You judge the quality of the service given in relation to the time when it was given. You do not put on the binoculars of hindsight and say 'It is now 1994 but this service was given in 1989. Let's apply 1994 criteria'. You do not. You apply the criteria at the time — in my example, that pertaining in 1989. It is very important to remember that. Cases may take a long time to surface and practices may have considerably modified since the time of the incident. A brain-damaged baby's claim might only be brought some 15 to 20 years after his birth — and an injury caused by a misdiagnosis and/or a failure to diagnose may not come to light for years after the condition developed. It is often quite difficult to remember and to check on what would have been done as a matter of practice at that time, though obviously contemporary publications are very helpful. Acceptable medical and pharmaceutical practices, including warning of possible side effects of drugs are constantly evolving, as the fund of knowledge grows and it is essential that when evaluating a claim that you apply the current standards that then prevailed and not those of a different period.

When a patient claims that the doctor has breached the terms of his

contract with the FHSA there may be a hearing before the FHSA. The complaint has to be made rather quickly within short set time limits. If this complaint is successful at the hearing it adds to the patient's strength in bringing a civil claim for compensation, provided he can prove that the breach has caused a significant injury. Happily, some of the worst breaches do not result in serious injury as the patient may have sought other medical help in time or a potentially disastrous outcome is avoided in some other way.

However, a successful FHSA hearing against a doctor will be one of the factors that the patient's lawyers would take into account when advising clients on the strength of their case when they are dissatisfied with the service provided by their general practitioner. That type of finding or one made following an analogous sort of disciplinary hearing could apply in a case brought against a pharmacist or any other professional person. It is very helpful to a client bringing a civil action if the professional person has been found wanting by the person or organisation with whom he has a contract or by his professional disciplinary body.

There then is the background of a contract, under the NHS; it will probably be a contract with an employer or for a GP, with the FHSA as a contractor for services. These are not just pedantic distinctions. Whether a doctor is an independent contractor or an employee will affect the legal status of the knowledge he acquires, the research he does in the course of his professional day, the ownership of the information and records he holds, and so forth. A hospital doctor is an employee. Whilst he carries out hospital medicine and practises under his contract of employment, his employer will be responsible for his conduct, including his misconduct and medical blunders, and by the implementation of crown indemnity, his NHS employers will have to pay out any compensation due to his patients from their budget. The fruits of the research which arise from his employment will normally not be his personal property to do as he likes with. A GP is a self-employed person; he is in a different position. Nonetheless, as we have seen he has duties to fulfil under his contract. The GP also owes a duty of care to his patients under common law and this duty is a separate legal duty (which the hospital doctor, pharmacist any professional person or tradesman) will owe to the patient or client and which is in addition to any express or implied terms of his contract with the FHSA.

Similarly with an NHS pharmacist. If, like me, you are one of these people who pays for a NHS prescription you may have the impression that you are entering into a contract with that pharmacist because you are paying money over the counter and getting drugs in exchange. You are not entering into a contract with the pharmacist. The contract that operates that payment is made between the Government and the phar-

macist and not with the patient, though the patient is a beneficiary and if he has means and is not exempt for some other reason he will make a financial contribution for each item prescribed. Of course, the situation is quite different when a patient buys an OTC product out of his own money, then he is making a private contract with the pharmacist. If the service provided by the pharmacist is unsatisfactory and has caused him injury, the patient then can sue the pharmacist in contract as well as tort.

Similarly, if a patient has gone to a private doctor for a prescription, then he has made a private contract with the doctor. But regardless of whether the prescription is private or NHS, in both cases, if the GP has been negligent, the patient can recover compensation if he can prove injury was the result.

A contract may provide for express requirements which go beyond what was previously thought to be a minimum reasonable standard of care. The fact of being in breach of an express requirement can give rise to an action in damages. One example might be that the doctor had undertaken to make a house call every day or to carry out a specific task in a particular way which went to the heart of the agreement. Contractual obligation may create a much tighter framework between the doctor and patient.

Another brief example: a gynaecologist-obstetrician who contracted with his patient to be present at the birth of the baby (given that he had sufficient warning to enable him to arrive). Say that the presence of the obstetrician at the birth went to the heart of the contract and the obstetrician knew this because the patient had explained to him that she was only 'going privately' for this reason — that she had suffered an awful experience at delivery on a previous occasion under the NHS — and she wanted to be sure that she would have his expert care and attention when the time came. He says 'Yes, I understand how you feel, and I agree. I give you my word. I will be there.' If he is not when he could have been, then that failure to attend will be an actionable breach of contract, per se. If I were that woman I would not pay the fee at all, or I would at the least demand a substantial reduction of his fee, even if the delivery was reasonable and the baby unharmed. However, if something goes wrong during the management of her labour that he should have been supervising and amending and could and should have avoided then that would be something further on which she could sue for compensation. You can see that all sorts of requirements can be laid down as a matter of contract, but a guarantee of a successful outcome for medical treatment is not an implied term of any contract and any doctor who expressly made it so, would be very foolish.

If you guarantee a particular outcome — and I come now to the selling of a product — and you either induce the person to buy it on those grounds, or you state as a term of the contract that the product will

achieve A, B and C, and it does not achieve A, B and C, then you will be in breach of your contract and a certain amount else beside if you knew or should have known it would never achieve A, B and C. This applies to the sale of a pharmaceutical product, medical device or any other goods. You must therefore be careful what you say when you sell something and not carelessly, recklessly or deliberately mislead.

There is relatively new legislation called the Consumer Protection Act 1987. We have heard about the directive which will require the insertion of package inserts for pharmaceutical products. Lying behind the directive, about the insertion of information pack leaflets, is the consumer directive of 1985, which led to the implementation of our Consumer Protection Act 1987. This provides that consumers are entitled to sue for compensation if a product is defective in that it 'is not as safe as persons generally are entitled to expect'. The question of whether a product is or is not 'as safe as persons generally are entitled to expect' will depend partly on its presentation and marketing. Is it labelled properly? Is it packaged properly? Has it got a tamper-proof top on it to prevent a child from swallowing the contents? Has the manufacturer warned people of the contraindications and of the signs which should make it clear they should stop taking the drug, say? Have you warned people when it is contra-indicated to be taken at all and of other drugs or substances with which it will or may set up a reaction or that its effects will be reduced if taken with another particular type of product?

I believe that the real reason for the introduction of the insert leaflets much sooner than was legally strictly necessary was the increased consumer right to sue for compensation in respect of an injury caused by a 'defective' product. I suspect that the introduction of the package inserts rather promptly has been a sensible, if defensive, attempt to avoid claims brought on the basis that there was a failure to warn of known side effects by the manufacturer. The Consumer Protection Act 1987 adds, if you like, to the remedies already available under common law, for injuries negligently and foreseeably caused by defective goods under the 'neighbour principle' enunciated by Lord Atkin in 1932 in *Donoghue v Stevenson (1932)*. (Common law is made up of case precedents developed by judges from basic legal principles.)

The law requires that a manufacturer must not be negligent; he must not market forseeably dangerous products. But most effective drugs may prove dangerous for some patients, and they may be particularly dangerous if misused. How safe do persons generally expect a prescription drug to be? How safe should they expect a drug to be?

The public need educating all the time. It is therefore important to get over to consumers that all drug products, if they are to be effective, do carry some risk, but this has been carefully considered in the marketing and prescribing equation.

If GPs want to encourage their patients to take the drugs and finish the course, even after the patients have read the product insert leaflet, it might be sensible for them to say at a consultation, 'When you get your medicine from the chemist, you will find a leaflet enclosed with it. I hope you will read it, but I also hope you take into account the fact that I have read it too and much more besides and that I have considered very carefully whether or not the risks of this drug outweigh the benefits or vice versa when deciding to prescribe it for you. I hope you will feel able to trust me. If you have any anxieties or problems, please contact me'. He probably will not say this, of course, but this advice does seem to be the way to overcome patient fears and anxieties. There is no reason why the GP cannot give out a little leaflet which says all this rather than repeat it every time! This is sensible customer relations. I am sure the private patient will get more time and may get more such advice, but that is human nature.

What information does the doctor or pharmacist have to provide to his patient to comply with his legal or implied contractual duties? Let us take the NHS general practitioner: If you look at the new National Health Service contract and look at the medical regulations which came out in 1992 — doctors have to —

> *'give advice where appropriate in connection with his (the patient's) general health and in particular about the significance of diet, exercise, the use of tobacco, the consumption of alcohol and the misuse of drugs or solvents...'*
> and so forth.

I think the Government has at last woken up to the fact that preventive medicine is a good idea; that prevention is better than cure; that if we can maintain a healthier lifestyle we will consult our doctors less. Bad news for the pharmaceutical companies? Or is it? If we all live longer, eventually old age will catch up with us and we will consume lots of medicines and medical services before we finally drop off the tree!

The idea is to encourage people to take responsibility for their own health. It is well recognised that people who are motivated are more likely to change their lifestyle and diet than those who are not. I am a lay person for this purpose — but I understand there is clear evidence that hypertension in people who are overweight and smoking is often most effectively improved by those people losing weight and giving up smoking rather than by taking medicines.

But how far do doctors try to persuade their patients to do this? Of course some people really do not want to know, and doctors realise this.

What does concern me a little is that, however well intentioned, a doctor may discourage a patient from consulting him, if every time he sees someone who is an addicted smoker and likes his tipple, or whatever, he tells him he shouldn't! That patient is going to be fed up if this is raised every time he goes to see his GP, particularly when he is feel-

ing a bit low. If the pleasures he has in a quite miserable life are his 'fags and drink' and every time he goes to the GP he gets a lecture about it, this could have a discouraging effect and stop the patient seeking help when it is really needed. It might, of course, work for some patients who will reform rather than face the doctor's disapproval. It is a matter for the doctor's clinical judgement, therefore, how often he raises life style issues. If he keeps raising them, the effect may be something like the cigarette pack warning. Everybody sees it, everybody knows it is there. It is mentioned so many times that perhaps it is just part of the scene but not effective and falls into being regarded with a kind of macho contempt.

How far have doctors got to go when offering this information? All professionals are judged by their peers in English law. Their competence levels are judged by lawyers only after taking into account whether they have provided a service in accordance with what is thought proper by a responsible body of practitioners in the same field. That is true of all professions: architects, solicitors, barristers, accountants, and so forth. With doctors, because there are so many different categories, they are judged by their specialist peers and not, for example by how long they themselves have been practising and their own particular limited or exceptionally great experience.

For example, the standard for all GPs will be the same and you do not take into account the fact that the chap is newly qualified or coming to the end of his practising life. There is an acceptable minimum standard of competence that must be met and that is it. It does not have to be the best standard; it has to be a reasonable standard.

This test was laid down by Mr Justice McNair in 1957 in a case called *Bolam v Friern Hospital Management Committee.* It was a case brought by a patient against Friern Psychiatric Hospital, which has recently closed as part of government cuts and 'care in the community' policy. The Bolam test is the fundamental plank of negligence claims. It is the standard test against which medical care and advice are measured and indeed is the test for all professional negligence standards, though not necessarily for commercial, trade practices.

You would therefore expect the GP to provide information to a standard that you could reasonably expect from a general practitioner rather than a consultant pharmacologist or an expert on blood, on dieting, on smoking, et cetera. But, curiously, notwithstanding that this would in any event be the test, GP standards of competence is written specifically into the contract — which is unnecessary as it would have been implied. However, it is clear that the lawyers acting on behalf of the GPs who negotiated this contract wanted no room for doubt on the point. You would have thought that good practice would require that when a general practitioner has a new patient he should reassess him. This is

theoretically correct and accepted. Alas, my own experience, from reading very many sets of GP notes, is that not only are much of them illegible or at best very hard to read and incomplete but that, sadly, when a patient changes doctor there is frequently no new assessment made at all. I therefore doubt that this new contract was doctor-driven to improve general GP standards but almost certainly initiated by the government and patient lobbies.

It is a sad reflection on the medical profession that the need for specific implementation of what should be good and normal practice has now to be written into GPs' contracts and pressed for most probably by government or patient groups rather than by the doctors themselves. What they have now to do is to

> *'seek details from the patient as to his medical history and, so far as may be relevant to the patient's medical history, as to that of his consanguineous family' — in plain English, 'close blood relations' — 'in respect of illnesses, immunisations, allergies, hereditary conditions; medication and tests carried out for breast or cervical cancer; social factors including employment, housing, family circumstances which may affect his health; factors of lifestyle, being diet, exercise, use of tobacco, consumption of alcohol, misuse of drugs or solvents, which may affect his health, and the current state of his health. Offer to undertake physical examination...'.*

Elsewhere in the contract, there are more requirements to screen patients; they have to consider the health of over-75s and take into account quite specific criteria. All of this is newly spelled out in the contracts, and it is all aimed at prevention of deterioration or early detection and at improvement in standards and health and perhaps in cutting care costs by operating 'a stitch in time saves nine' policy. One of the things GPs have specifically to do with the over-75s is to consider the drugs they are taking and reassess their prescribing. This term of the contract reflects what should have been good practice and was clearly ignored by many GPs. All too often elderly people have acquired a battery of drugs that they are taking on a repeat basis without proper reassessment of their condition and the interaction of the drugs themselves and any changes in circumstances. Drugs have been added one after the other, and frequently they are contra-indicated or unhelpful to the patient when taken together or in the quantities prescribed.

I have explained that GPs now have to talk to their patients about overall conditions of health, which is a sort of promotional, pre-emptive attempt to improve health and reduce the drain on the health care services (and social services). But they have traditionally had to advise people on the treatments available and whether they should be referred for further advice, and so on. Again, that advice has to be given only to a GP's standard. The advice on the contra-indications for medicines will be to a GP standard; it will not be to the standard of somebody in a

teaching hospital who is a pharmacologist with a particular interest in this particular drug. He will not be expected to reveal every fact that is known to the pharmaceutical company. I am sure that most GPs do not know every possible contra-indication. There is evidence that most GPs tend to prescribe from a fairly narrow range of products anyway. They prescribe those drugs which they feel comfortable giving out and they are further limited by the government's limited list. I do not have the precise evidence to hand, but I am told that the most importance influence on GP prescribing, apart from drug reps, is what they learned when they were at medical school, which is quite alarming if they left thirty years ago!

GPs have to advise on whether a drug is suitable. Sadly, they do not normally discuss alternatives, though no doubt they only prescribe what they believe to be suitable: they mostly say 'I will prescribe you 'X'. Please take it three times a day. Make sure you take it with your food', 'before your food' or 'after food', 'not with alcohol' — and that is more or less it. In my personal experience, they are unlikely to give you a great deal more information. If you are fortunate, you can go down to the pharmacy and the pharmacist will come out and give extra information or reinforce what the doctor has told you and say 'Do be sure to take it this way' or 'that way'. That is the good pharmacist, who wants to bring some matters s/he thinks important to your attention or to be sure you are not already taking a drug which could set up an adverse reaction with the new prescription or nullify its effects. These days the keen pharmacist may say 'There is a leaflet with this drug. It is well worth your while to read it. If you have any queries, go back to your doctor'. If pharmacists are concerned about the prescription, they may want to telephone the doctor. They will tell you to come back later because 'it isn't in yet', or something to that effect. That is what the pharmacist is supposed to do — to provide a safety net. They are supposed to check that the prescription appears to be correct on its face; that there does not appear obviously to be a misprescription either as to the drug or the quantity prescribed. Do they prevent more harm than they create? I do not know.

I find that pharmacists very often do come out. How far must they do this? This is very much a matter for their clinical judgement (along Bolam lines). It is a matter of what other pharmacists do. It is the level of competence of the profession. In this country standards of care are largely profession led. Some breaches might be so gross, however, that it will appear obvious that this information should have been imparted.

The case I have in mind where a pharmacist fell below a standard is the well-known one of *Prendergast v Dee*. The doctor was also negligent. He wrote the prescription very badly; the pharmacist misread it in a hurry, and they were both liable because the wrong drug was dispensed

(along with two others which should have set alarm bells ringing — but did not) and the patient was seriously harmed in consequence.

I suspect, stepping into a lion's den here, that as much trouble may be created by a pharmacist misreading and misdispensing, as doctors do by poor writing and so on. In fact, I think most pharmacists must be very good at reading these awful scribbles. They do say that pharmacists become suspicious that a prescription is forged when it is legible!

While the legal implications of providing health information are complex I hope that this brief overview will have clarified some of the key conceptual issues and practical questions involved. I have explained that how much information is provided is profession-led on the whole. Under his GP contract, the doctor is now required to provide more unasked advice on healthy living and must do this to the standard to be expected from a GP. Similarly pharmacists must act in accordance with the standards imposed by their peers. Of course, the two standards could clearly differ.

# The role of pharmacists in the provision of health information to the consumer

Dr Philip J Brown

One should look very carefully at the title of this debate, because it says 'the role of pharmacists in the provision of health information to the consumer'. I do not know whether this means their role as professionally qualified pharmacists, or the role of pharmacists plus unqualified pharmacists' assistants. It is important to get our terms right. One of the key issues is what role do pharmacists currently have in the provision of health information to the consumer?

Let me try to set the scene for this by describing what actually happens in practice: that is what matters. We hear a lot about the theory of the situation, but when it comes to practice what is going on? I will start by talking briefly about dispensing and prescribing, and then go on to the provision of over-the-counter medicines.

If you are unfortunate enough to be sick and consider it is worth a visit to the doctor, you consult the doctor who has been appointed to treat you where you have a one-to-one relationship in that magic doctor-patient relationship. In that environment, you rely on his opinion. I believe there should be a health warning associated with that opinion, because the chances are 50/50 that s/he will get the diagnosis right or wrong; thereafter the chances are 50/50 as to whether you will be prescribed the right medicine. You may laugh, but I am sure everybody who examines their own experience and the prescriptions that have been given to themselves and to their relatives will come out with a fairly positive: 'Yes, that is very likely to be the case'.

Unless s/he has the advantage, or disadvantage, depending on your point of view, of consulting in a dispensing doctor's practice, the patient will then go to the pharmacist, possibly two or three miles away, where s/he is probably not known. Certainly in the city environment strangers walk into pharmacists' all the time, and give prescriptions to the pharmacist to dispense. The pharmacist has no knowledge of who this person is, whether the person actually is the person described on the prescription and seldom asks for any form of identification. The prescription is then dispensed, in what has become a 'pick and stick exercise'. The pharmacist 'picks' the pack off the shelf, 'sticks' a label on it and gives it to the patient. Hopefully, a little information may then be given to the patient. Whether or not the information is relevant is another matter.

This exercise is called 'dispensing', for which we need pharmacists who are currently required to have a three-year university degree, and who shortly will be required to have a four-year university degree. In fact, that university degree produces pharmaceutical scientists. It does not produce people who are good at talking to patients over the pharmacy counter: that is very often left for what is called postgraduate education. Only the very enthusiastic, and the good and the great are willing to participate in such educational activity on a life-long basis.

The reason why we have pharmaceutical scientists providing this dispensing service is because the universities can only get the money needed to offer a pharmacy education if the study course has a very high scientific content. The requirements are such that the scientific content of the university education must continue to increase, so we will get increasingly knowledgeable pharmaceutical scientists 'picking and sticking'. That is the pharmacy dispensing scenario today.

What we do not have is pharmacists who are really participating in the national provision of day-to-day pharmaceutical healthcare. The reason we do not have this is because there is neither the infrastructure nor the information services available to the pharmacist in the dispensary which ensures that when the patient goes into the pharmacy with his prescription the pharmacist has any background medical information on that particular patient. The pharmacist is part of the dreadful scenario from which we are emerging of individual practitioners and individual pharmacists doing their own thing. The individual practitioner model has served the community reasonably well in the past, but anybody with any kind of perspective on the future will look back on that time and say it is not surprising that we had such irrational diagnosis, treatment and prescribing.

I will give you one example which I was told recently by a young pharmacist. He was employed in desperation by a general practitioner group because they could not control the costs of prescribing under PACT. This young man had a field day sorting them out. The one prescription which really came to his mind as being the pinnacle of irrational prescribing involved a patient who had been diagnosed in the middle of 1992 with a duodenal ulcer. The doctor concerned had decided that, in order to prevent the recurrence of this condition, the patient should receive a prescription for an anti-ulcer drug plus antibiotics, which comprised omeprazole plus Amoxil three-times-a-day. That prescription became a repeat prescription from the middle of 1992 until this young pharmacist, in October 1994, asked: 'What is this all about?' My question is what dispensing pharmacist over the two-year period raised his/her hand to say: 'What is going on?' Clearly there is neither the mechanism nor the awareness in the dispensary of these kinds of issues.

I accept that the pharmacist is in a position from time to time to provide a safety net, but only when something grossly incompatible comes across his/her dispensary, or when the dosaging is clearly wrong or some such thing. But this is not a reliable safety net. We have 30 per cent of patients going into hospital with iatrogenic disease caused by the mis-prescribing or mis-application of dispensed medicines.

If you look at matters rationally, whether or not we have pharmacists, we need a very radical reform of the whole of the pharmacy dispensing process. I am extremely pleased, as I am sure you all are, that we are going to have patient package inserts in all the medicines. I only regret that the pharmaceutical companies in this country are going to use the five-year period of grace which they have, as their various product licenses are renewed, before they put patient package inserts into all their packs. I would like to feel that there is a conscience in the pharmaceutical industry; that the companies all want pack inserts as soon as possible, so that patients are being treated more rationally and more effectively.

Let us move out of the dispensing niche into another niche: over-the-counter medicines. We all know what happens when we go into a pharmacy and ask for an over-the-counter medicine. If you know what you want, you go in and ask for it, and you get it. The only involvement of the pharmacist in the vast majority of the cases is 'the wave and the nod'. I do not know whether you have seen it. The wave is when the product is picked up by the unqualified assistant and waved at the dispensary. In response, a little grey-haired lady or gentleman puts his/her head over the dispensary top and nods!

I do not know how many lectures are carried out in pharmacy schools on dispensing, to work out exactly what the size of the nod may be, or the extent of the nod, and how vigorous or otherwise it may be, but that is the extent of pharmacy control with the sale of over-the-counter medicines. If you do not believe me, you can go into Boots in Kensington where they have a magnificent dispensary. They also sell homeopathic medicines — products in which we all of course believe in terms of efficacy! I must admit, however, that there you may not even see the nod. I have been in that pharmacy and I have bought Zovirax for my wife. I have also bought Pepsidase-C. You name it, I have been able to buy it, not only in that pharmacy but in several others, without any involvement by the pharmacist in the purchase. The fact of life is that these OTC products are consumer products, safely sold by unqualified people.

The Consumer Association has periodically investigated pharmacies to discover what has been happening with OTC sales and has found out what I have just told you. Pharmacists have felt extremely upset that they have been so discovered, because clearly the pharmacist — with all this

magnificent education — should be out there supervising the sale. In response to these investigations the Royal Pharmaceutical Society has decided to regulate matters: to provide some guidance and guidelines. In future, when the pharmacist is visited by the customer, there is a procedure which is applied so that the pharmacist can be seen to be in control. This procedure will also apply to unqualified staff, so that they too will be seen to be controlling the sale.

This guidance is very interesting. It presently appears in various bar chart and other pictorial forms in the *Pharmaceutical Journal* and in other publications. The prime purpose of it is to help the pharmacist to decide whether or not the sale should take place. There are all kinds of rigmarole procedures, some of which are quite impracticable. For example, there was a complaint relating to the sale of certain kinds of products where a pharmacist said he did draw the line at asking his young lady patients in public and over the counter when they had last had sexual intercourse. He felt that was something which was not properly discussed in public before he provided certain products.

When you get to the situation where it is agreed under the guidelines that yes, the patient/customer can be sold the product, suddenly the guidance stops. We are left with the critical issue of what advice should the patient/customer be given? The whole purpose of this exercise is that the pharmacist gives guidance to the customer. What products are they to sell and what instructions and advice is to be provided? The guidelines are silent on this subject.

I recall a discussion I had with an eminent pharmacist who has been in and out of pharmacy 'power'. She told me that when, for example, she had patients come in with hyperacidity she always gave them Asilone. I asked: 'Why do you always give them Asilone?' She said 'because it is the best product'. I asked: 'What about these H2 antagonists and other products like Gaviscon, or even Rennies?'. She said: 'No, I do not give them those; I give them Asilone'. I call this 'pharmacy tyranny'. What kind of evidence does she have on which to base that advice?

If you look at the pack information put out by the manufacturers, you will find that they will say their product has this or that action. But there is, for example, no comparative clinical data available to compare various forms of hyperacidity treatment. If there was, I would question the statistical validity of that information, given the varied nature of the patients who are being treated and the very low doses of therapy involved. You, therefore, finish up with the advice which is simply *ad hoc* advice based on what the pharmacist thinks.

What is it that the pharmacist thinks and what motivates them? There was a piece of market research undertaken by a British company, which will remain nameless, who were considering introducing an H2 antag-

onist as an OTC product. They held group discussions with pharmacists, and asked on what basis they would recommend this product in preference to other products that were available for the treatment of hyperacidity. The pharmacists said it all depended on the profit margin, the amount of the advertising, and the amount of patient information. Is that a sound basis for the service pharmacists are giving? I think not.

## Linda Stone

In earlier papers, we have heard quite a lot about some of the problems in providing health information to the general public. I will start by trying to explain where I fit into this scheme. I am sure some of those who are healthy and fit are not fully familiar with what the majority of my profession are trained to do.

What is my role as a community pharmacist in this field? What makes me believe that the community pharmacist, properly used, is a crucial link in the information chain, and that the community pharmacist is the most readily accessible health care professional?

- There are some 12,000 community pharmacies in this country each with a minimum of one pharmacist on the premises. These pharmacists are virtually all open from 9 am until at least 5.30 or 6 pm on five and a half to six days a week, and many are open for much longer hours.
- People are used to coming into a pharmacy. They do not consider it to be as intimidating as a doctor's surgery.
- There is no need to make an appointment to see the pharmacist.
- Over 6 million people visit community pharmacies every day. Of those 6 million, over 1 million are seeking health-related advice.

What does a community pharmacist do? What I do not do is spend my time counting tablets, pouring liquids, licking labels and sticking them on — a job done nowadays by trained support staff, some of them trained to BTech level, some trained by professional and vocational training. My total concern, as the most accessible member of the health care team, is for the patients and customers who come into the pharmacies where I work.

What gives me the right to comment on the problems of conveying information, to give what I believe to be a realistic overview of the requirements of the patient? I am a practising community pharmacist, and have been for the last 20 years. For a number of years I have worked as a self-employed locum, which means that I travel around and experience vastly different styles of practice, serving patients from almost every conceivable social class, age group, level of education and understanding. Everywhere from the yuppie suburb to a sleepy market town, from a city centre to an out-of-town supermarket, from Winson Green Prison to an inner city area, where, I estimate 95 per cent of the patients speak English only as a second language, if they speak it at all. I deal with real patients on a day-to-day basis, answering their queries and satisfying their needs for information.

Modern community pharmacy is about promoting and maintaining good health as well as treating ill health and caring for the community

as a whole. The increase in original pack dispensing and the widespread use of computerised labelling systems, which are very sophisticated and the majority of which hold patient medication records, have released time for the community pharmacist; time which is used to counsel and provide information to the best of our ability to ensure that people understand how best to manage their condition and maintain their health.

Part of my role is to make sure that the patient presenting a prescription or making a purchase receives the correct product, correctly labelled and packaged, as promptly as possible, and that they know and understand how to use it. For a dispensed medicine, the first part is easy, even allowing for problems such as incompatibilities between medicines, illegible writing, computer errors and overdoses.

For any medicine, ensuring understanding is the difficult part. How do you counsel a patient if somebody else is collecting their medicine? How do you communicate if they are illiterate, deaf, do not speak English, or blind? In the United Kingdom we always fix an individual label to each dispensed medicine. This label should contain the dosage instructions specific to the patient concerned. In addition, a number of years ago the profession initiated a system of product-related cautions and warnings which are included on the label as a matter of good professional practice. A list of these is included in the British National Formulary *(BNF)* as Appendix 9. The increasing potency of modern medicines makes this information critically important. I am only too well aware that this was just a start and that, for many patients, labels alone do not provide sufficient information. The object of giving patients more information is to aid their understanding and hopefully their compliance, and so improve their health.

Between 37 per cent and 54 per cent of what the doctor tells the patient is forgotten when they leave the surgery *(Ley, 1979)*. Extrapolate that to the one million prescription items which are dispensed every day in England and Wales and you have an idea of the size of the problem faced by my colleagues and the potential number of patients with problems of understanding and compliance.

Counselling alone does help, but it is not enough. Patients, although more relaxed when they reach the pharmacy than the doctor's surgery, are still liable to forget a significant proportion of what is said. The same may well apply when the medicine is sold.

As reported in the paper by Sharon Gibbs, surveys have established that a majority of patients find information leaflets to be useful. European legislation *(Council directive 92/27/EEC)* means that all dispensed medicines and the majority of non-prescription products must have a leaflet within the pack. The timing on this will depend on how fast the company reapplies for its product licence if it is an existing prod-

uct. But it will happen, hopefully, within the next two to three years.

It is important, however, that leaflets are seen as a supplement to labelling and counselling. They are not an alternative *(Royal Pharmaceutical Society of Great Britain, Working Party on Information to Patients, 1986)*. Good, properly designed leaflets do reinforce the information which is being given and do improve compliance and health. Coincidentally, they may also reduce waste, which is a significant factor in today's economic climate, both for the patient who is paying for the item and for the Government which is paying for the dispensed medicine.

The patient only wants one thing — to understand — and that is the problem. In 1980 a study was published entitled Understanding Labels — Problems for Poor Readers *(Adult Literacy Support Services Fund, 1980)*. This study was prompted by a particularly horrifying incident. A mother, bottle-feeding her new-born baby, did not realise that she had to increase his bottle feeds as the weeks went by. She was not able to understand the instructions on the baby milk packet. The baby, otherwise well cared for, starved to death. Hopefully, that would never happen nowadays. But it is essential that leaflets, labels and information are understood by the target audience. In fact, all written and verbal information must be appropriate and carefully designed with the recipient in mind. In the words of St Paul 'Except ye utter by the tongue words easy to be understood, how shall it be known what is spoken? For ye shall speak into the air.'

At least one million adults in the United Kingdom have a reading age of less than nine years. The population of the United Kingdom is not unique in this respect. Work in the United States has identified that 47 per cent of adults there score 'low' on literacy levels and are deemed unable to function effectively in the workplace.

The reading centre at Reading University states that there has been no research to determine the average national reading age in this country. What is known, however, is that an average reading age of eight and a half to nine years is consistent with this country's best-selling national newspaper, the Sun, which has a circulation approaching 4 million and is read by about 13 million people every day.

It gets worse. Eight and a half to nine years applies to when people are reading about known knowledge. Present these readers with information, verbal or written, about which they have no prior understanding, such as a newly diagnosed health problem, and it is considered that it should be compiled for a reading age of some 18 months lower; that is, seven to seven and a half years. Those of us who are literate and educated must find this hard to grasp — preparing information on important issues for adults with a reading age of below seven and a half. Complex concepts are difficult to convey simply and over-simplification

may mean that the more intelligent amongst us misunderstand.

In February 1994, the Adult Literacy and Basic Skills Unit reported that 16 per cent of the adult population, some 8 million people, have severe problems with reading and writing. This includes a number of people who may or may not be able to read, but as they cannot speak English they are unlikely to be able to read it. The problems of ethnic groups cannot be ignored. Sources estimate that between 25 per cent and 35 per cent of some immigrant communities are illiterate.

I referred at the start of this paper to an inner city pharmacy in which I have worked. There I estimated that between 90 per cent and 95 per cent of the patients, in this very busy dispensing pharmacy, did not have English as their first language and at least half of these do not appear to speak or understand spoken English at all. I can only hope that either the doctor had given them the instructions, which they had remembered, or that there was another adult in the household who could translate the label and leaflet. In fact, the translation is more likely to have been carried out by their children. This is confirmed in a study of Indian and Pakistani hospital in-patients by Kaur and Dobrzanski (1988), where it was found that 54 per cent of them relied on children to read the pharmacy label, placing an intolerable responsibility on sometimes quite small children, whose understanding and reading ability is unknown and, coincidentally, undermines the safety message that 'all medicine should be kept out of reach of children'.

I understand that some time ago the ABPI approached ethnic minority community leaders about the need for leaflets in different languages. The response at that time indicated that there was not a problem. It was stated then that 'there is always another member of the household who can read and translate the information'. With what loss of meaning? There was another problem. Many of those who could not read English could also not read in their own language. For an immigrant to admit that they cannot read English is acceptable, but for them to admit that they cannot read their own language is not acceptable. The individual would lose face. Hence leaflets in ethnic minority languages were of questionable benefit.

The provision of advice with the medicine that is either dispensed or sold is therefore very important. Good leaflets for patients will only partially replace this part of a pharmacists job. However, it is only one part of my role. What about the time spent promoting good health? *(The Health of the Nation, 1992)*. The problems of communication are the same.

There are in existence a variety of types of leaflet we can distribute as an adjunct to our advice. These come from a multiplicity of sources and they can form the basis of a variety of health promotion campaigns. One example is the Pharmacy Health Care Scheme which commenced in

1986 with the support of the Royal Pharmaceutical Society of Great Britain, the National Pharmaceutical Association, the Health Education Authority and the Health Education Board for Scotland. It is now well established and distributes at regular intervals leaflets to each community and hospital pharmacy. The topics covered are extremely varied: from family planning to drug abuse and breast cancer to head lice.

In conclusion, community pharmacists are well-equipped to carry out the role of providing verbal and written information due to their undergraduate education and pre-registration training *(Nuffield Foundation, 1986)*. Participation in continuing education courses always underpin our activities. We will and do use whatever suitable aids are available. But information must be information which communicates, because information in whatever form for its own sake just creates an ineffective means of communication which frequently confuses. The name of the game is to promote health, not confusion.

> *'If any man were to ask me what I would suppose to be a perfect style of language, I would answer, that in which a man speaking to five hundred people, of all common and various capacities, idiots or lunatics excepted, should be understood by them all, and in the same sense which the speakers intended to be understood'.* Daniel Defoe

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## Derek Prentice

Let me start off by saying what consumerism is all about. It is about empowering the consumer through choice. We are totally committed to a competitive market place to enable the consumer to be empowered, to make up their own minds about what they do and do not want to buy. But choice requires one important thing, if it is to be realistic. It requires information. Informed choice is the only real choice worth having.

It seems to me that the community pharmacist, or any other kind of pharmacist, has an important role in providing consumers with information about the products they are dispensing and perhaps information about general health care. But they are not alone. There are many others out there equally well able to give it. I hope to show in a moment that, in many areas, they, that is pharmacists, are failing miserably in what they are trying to do. However, it seems to me that pharmacists have a glorious opportunity to use the advantages of their profession, training and standing in the community over other people who might be giving such information in the future.

If pharmacists adopt a role for themselves which may help them to sell other products then they have to provide consumers with appropriate and proper health information in a manner that the customer wants and can understand. This will enable them to take advantage of their competitive place in the market place and actually deliver to the consumers good products and information, which will make the consumer want to come to them rather than to go somewhere else.

But there is a long way to go. Many pharmacists are open from nine to five-thirty, and a few longer than that. Pharmacists need to be reminded that we now have seven-day trading and a bill will be placed before the Commons today, allowing 24-hour trading. If pharmacists want to give information to the consumers, they had better go the way consumers want them to go. I can tell you that that is not from nine to five-thirty; it is probably 24 hours a day. At a minimum it is the hours that most supermarkets are open for, and of course that includes Sundays.

It is important to realise that if you want to give consumers information, you have to be prepared to give it to them in the form that they want and when it suits them rather than when it might suit the pharmacist.

Consumers have a number of rights: access, choice, information, redress and safety. Choice is important because it is the one thing that actually empowers each and every one of us to be able to say 'No, thanks. I don't like what you have to say. I don't like what you haven't

bothered to tell me. So I will take my custom elsewhere'.

I have referred to information. Safety is also an important issue, particularly in the area of medicines. The one issue that worries the Consumer Association and a number of other consumer organisations is that pharmacists are in an important position; they have a position of influence and, in many ways, power over their customers, given that the customer looks to them for good professional advice. If pharmacists are to take advantage of the competitive market place to which I have referred, given that the choice of products consumers are able to buy is being widened all the time (I refer here particularly to OTCs which in our view ought to be made widely available at as many outlets as possible, with or without a pharmacists) then pharmacists have to start taking their role in the delivery of that information seriously. Not only in terms of opening hours, information provision, et cetera, but in seeking to show that they have an important and professional role to play in protecting the safety of the consumer in the information that they give, or the manner in which they sell products.

You will be aware of the professional concern at people like us going round, saying 'We want more and more medicines sold as widely as possible — in supermarkets, high street stores, and so on'. They argue that there are important safety issues to be considered and that pharmacists should be involved. Maybe that is so. We would want to encourage pharmacists to adopt a more pro-active role in delivering information in a modern manner. But we have major concerns, about the ability of pharmacists to take their role seriously, not least when it comes to protecting the interests of the consumer.

Consumers' Association and our colleague organisation at the College of Health have for some 20 years examined the claims pharmacists make to be allowed to have a restrictive market operating to their advantage. We tend to be opposed to any form of protectionism, particularly when professionals are calling for it. It normally means that it is not the customer who is being protected, but the profession.

In 1974 we went round, with experts, looking at pharmacy sales, buying particular products that had particular dangers for the consumer. We went in and asked for these products. We told the people concerned that we had certain symptoms - symptoms which could have been open to misinterpretation in terms of the kind of advice that should be given; it was particularly important to listen clearly to what we had to say because the wrong product could easily be given. We found that there was a lack of clear advice to see the doctor when necessary; there was ineffective and inappropriate medicines recommended; medicines sold as 'The Mixture' with no details given about the ingredients, at least that has changed now, thank goodness. Advice from pharmacists was not available in one in four visits. Not only was it just a nod or a wave of

the hand; on one in four occasions they were not even there to give that nod.

As a result, we concluded that improvement was needed in the quality of service to ensure consumers' confidence. If the pharmacist is to play the important role that they ought to be playing, then consumer confidence is the key. It is not easy to get consumer confidence but it is remarkably easy to lose it.

In 1984 we carried out the same kind of exercise. We found things had improved. There was clearer, more frequent advice on when to see a doctor; there were better and more appropriate questions regarding symptoms; pharmacists were ready and able to give advice in four out of five visits, and although more medicines were being sold there was a high failure rate to check what medicines were already being taken. Overall, things were looking up. There was still a need for pharmacists to follow their own professional guidance more consistently, but undoubtedly there had been an improvement.

In 1987 the College of Health conducted the same exercise and found not too dissimilar results. In the 1987 conclusion, again the same comment — there was room for improvement.

Then we come to 1994. We went back and did exactly the same kind of exercise. Things were not the same. There was little attempt made to find out what the customer wanted. Sales assistants failed to consult the pharmacist, even by a nod or a wave. Many pharmacists failed to ask about symptoms. The customer was often sent away with the wrong product or without appropriate safety warnings. We concluded then that so-called 'supervision' of the sale of pharmacy medicines was little more than a sham, and that there was a long way to go before consumers could be confident that pharmacists were providing adequate safety checks.

Bear in mind that this is not something the consumers are calling for. This is something that the pharmacists themselves claim they are doing, and they claim special privileges for themselves in the provision of such medicines. They do not want to see the wider dissemination of those sales.

It suggests to us that, given the failure to provide information on use, the risk of some of these medicines doing great harm is not that high. There is little argument as to why these medicines should not be on sale elsewhere. But that also has risks, we accept. The opportunity to get wider, good quality and good advice and information will probably diminish in the short term — but probably only in the short term because the market will undoubtedly take care to provide that information in another way, whether it is by a professional pharmacist or not. But the results of these surveys undermine the claim that pharmacists have a major role to play in the provision of health information. That

they should, we agree. That they have an important role to play in giving such information, we agree. But they have a long way to go to start delivering that professionally and adopting the expertise and advantages that a normal commercial market place would undertake to deliver such information.

We have already heard about the difficulties of getting this information across. Marketing men and women in other product areas do not have that problem. Many children are in no doubt whatsoever how to play the most complicated of games. They are the only people that we commonly hear are able to operate the video machine and do not forget that quite complex piece of information. Many of the toys that three- and four-year-olds play with are complicated. Look at Lego; look at the way they understand what sweets they want.

If pharmacists want to take up the important role that they have - and they undoubtedly have it — in the provision of health information to consumers, they have to do better. The poor and unprofessional approach revealed by the Consumers' Association and others has to be reversed for it will undermine consumer confidence in your role as pharmacists in the provision of such information. It will undermine it very rapidly indeed. It will also enable people like us, and others, to question why OTC medicines should not be made available anywhere to anyone who wants to sell them, because the pharmacists are proving too often it does not matter — they are not there to do it anyway, or merely give a perfunctory nod.

You have to start adapting and delivering your services in a rather more competitive and commercial way than you have done to date. You have to start opening — not when it suits you but when it suits the customer. You have to start learning the lessons of marketing other products in a way that it gets information across to the consumer.

That pharmacists have an important role is certain but they have a very long way to go to justify having that role for much longer.

## Dr Felicity Smith

Pharmacists have a very long history as health advisers to the public. It is a history which has gone through many changes, related to changes in the delivery of health care services, developments in technology and so on. And change continues. Government policy now recognises the importance of primary care and health promotion, is encouraging individuals to take responsibility for their own health and consumers to demand more information. In these developments, I believe that pharmacists could and should have a pivotal role.

In this paper I will first consider current pharmacy practice, then I will consider some priority relevance and what we have to think about to ensure that we provide an effective and an efficient service in the future.

In the last couple of decades, the role of pharmacists as health advisers has attracted a lot of attention from researchers. Pharmacists, because of the nature of their advisory work and their accessibility to researchers, are open to scrutiny in a way that other professions are not.

A number of studies have looked into the number of requests for health care advice that pharmacists receive, including those that relate to the use of over-the-counter medication.

An average pharmacist in Britain advises around ten clients a day on minor ailments. Country-wide this corresponds to over 100,000 consultations per day or 30 million a year. It is an activity that is worth some attention and these figures have been reproduced in different studies in different parts of the country. It also refers to consultations undertaken by pharmacists themselves rather than their staff. The range of symptoms presented in these consultations will be familiar to most pharmacists.

Figure 1 shows the main categories of problems discussed with pharmacists in over 700 consultations that occurred in 64 community pharmacies in London. As may be expected, pharmacists were commonly asked to advise on upper respiratory symptoms which comprised almost a third of cases; skin problems were common, as were gastro-intestinal problems. These symptom groups accounted for over half of all cases. A more detailed examination of symptoms presented, however, shows that these broad categories conceal a wide range of different permutations, which require different responses from and skills of the pharmacist.

Figure 2 shows a more detailed breakdown of the skin symptoms. As you can see, these include short-term self-limiting problems, problems which could develop into something serious, chronic problems which may require long-term management, accidents requiring first aid. For some of these problems, underlying causes and preventative measures should be considered.

FIGURE 1 **Symptoms presented**

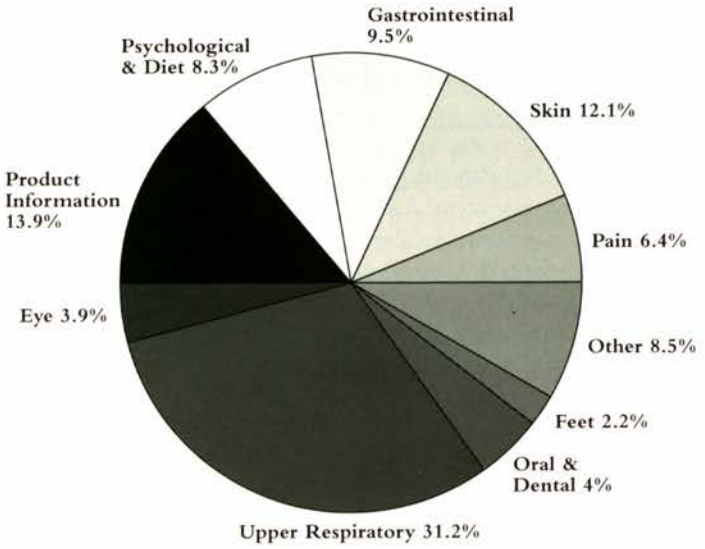



FIGURE 2 **Skin symptoms**

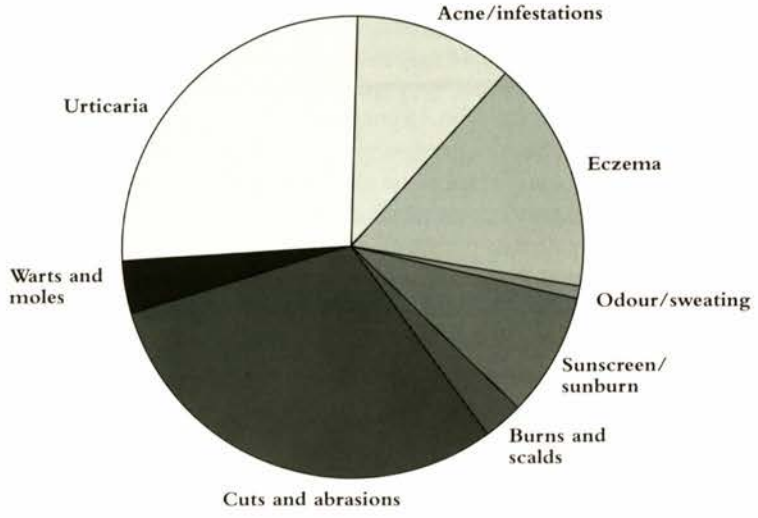
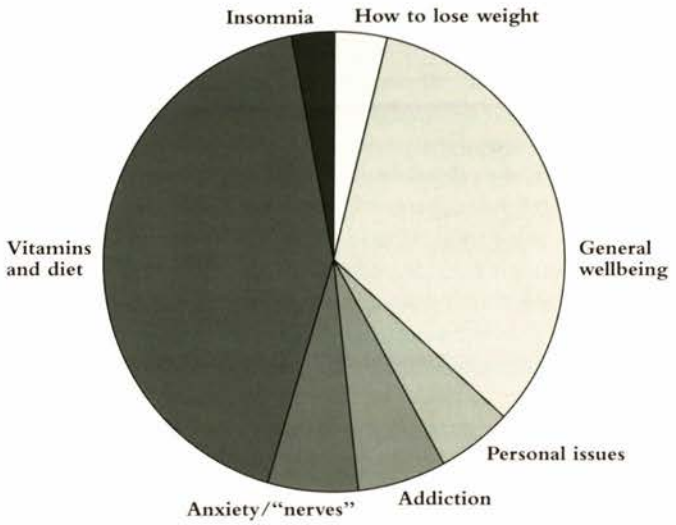


FIGURE 3 **Psychological and diet**




Looking at Figure 3 we see that a similar picture exists for other sorts of symptoms. So the range of symptoms may at first sight seem very familiar and rather mundane. However, the findings show that clients believe it appropriate to discuss a wide range of different problems with pharmacists. Symptoms also classified as psychological are presented. It could be argued that all cases have a psycho-logical and social component and these consultations include discussions of general well-being, anxiety, insomnia, drug dependence and weight problems. They demonstrate that as well as requiring a broad clinical and pharmaceutical knowledge and skills, pharmacists also require good communication skills and an awareness of the psychological and social aspects of health and ill health.

There have also been a number of initiatives to assess the quality of the advice pharmacists give. I hold very strongly to the view that if pharmacists are to promote themselves as health advisers they have a duty to ensure the quality of advice is high. Many of the studies that have attracted wide publicity have often been narrow in their scope and the findings of other studies employing different methods have sometimes come up with very different results. Nevertheless, the findings have been mixed and I think we must acknowledge that these studies uncover some causes for concern.

The individuals most conscious of these shortcomings, however, are within the profession. Through developments in recent years in undergraduate curriculum, postgraduate education, research and practice ini-

tiatives, pharmacists are endeavouring to address these problems. Although these findings are not always as good as we would hope, we do not know that they are any worse than advice that is received elsewhere.

Other characteristics of consultations will also be identified. Pharmacists are usually immediately available to clients who come in and request advice, and they are generally attentive to clients' questions — though, I agree, they probably ask too few themselves. The consultations are not usually dominated by a professional, and it is often identified as a feature of pharmacy that clients are able to express their own concerns and question a recommendation or a course of action.

Pharmacists believe that requests for information are increasing and have good reason for believing this. Pharmacists have been fairly active in promoting themselves as health advisers; there is general acceptance that consumers in the 1990s want more information about drugs; medicine has become less paternalistic in outlook; health practitioners are more likely to subscribe to shared decision-making, which involves giving more information and the more information you give people the more questions they will ask.

As more products are re-classified from prescription-only to pharmacy medicines, more people who would have consulted a doctor may discuss their symptoms in a pharmacy. The re-classification of drugs does raise a number of other questions concerning the rationale of the controls on sales of drugs or public attitudes to them. If we say only products which could be safely handled by patients should be available over the counter, then we have to ask who is the patient? How safe is 'safe'? Aspirin, paracetamol, antihistamines, codeine, H2 antagonists, can all mask potentially serious health problems and none are safe, irrespective of use. Of course, all products should be supplied with written information — a label, package insert or leaflet — but this alone would be insufficient to ensure appropriate use. The question is do these potential problems mean that the public should not be able to choose their own course of action? I would be interested to know if the Consumers Association think that these same arguments should apply to prescription-only medicines as well.

There are many uncertainties about the use of over-the-counter medications. For instance, people may assume that because they do not need a prescription they must be safe. Noel Hall reports in his paper that 36 per cent of people think that only medicines received on prescription are effective. If people do not believe they are effective, they may well believe them to be safe, and cases of inappropriate use are probably higher. We do not know about that.

Individual pharmacists vary in the level of supervision they accord to pharmacy medicines. Some give only minimum observance to supervi-

sion laws, while others endeavour to satisfy themselves about the appropriateness of the use of a product. This variation may be a result of business constraints; it may be an indication of the pharmacist's perceptions of the risks of the drugs. It may also reflect pharmacists' beliefs about the wishes and expectations of clients for advice.

In additions, pharmacists cannot ignore the ethical considerations. Should they always recommend the cheapest suitable product? Perhaps in pharmacy we have the converse situation to that developing in medical practice, where it may benefit the doctor, especially fund-holders, to give out the cheapest product when a more expensive one may be advantageous to a client. If it is unethical to recommend an expensive product, is it unethical to sell one on request? What responsibility does a pharmacist have to inform a client, and does the client have the right to purchase whatever they wish? GSL, pharmacy medicine, or even prescription-only medicine.

Indiscriminate supply of drugs could mask symptoms in those people seeking help. Perhaps it is not too cynical to suggest, however, that our 1990's health service cannot cope with everybody's problems anyway! Any health care system should have mechanisms to promote good health and facilitate the appropriate use of drugs. To do this there must be some sense in having single centres where there is some expertise to discuss their use.

Most of the research regarding the role of pharmacists in health information has concerned over-the-counter medication. There have been a number of recent developments in community pharmacy to improve the quality of services relating to the supply of prescription drugs. Many studies have highlighted the high levels of iatrogenic disease. Drug-related problems which include adverse drug reactions and non-adherence account for a high proportion of hospital admissions and many deaths. This fact reveals a deficiency in our health care system. Monitoring by prescribers is clearly inadequate and, if pharmacy is a safety net, although it may identify some problems it is not as effective as we might hope.

It seems at present that neither prescribers nor pharmacists are urged to give adequate attention to addressing this problem. Better information for consumers and more discussion with them may uncover many problems before they become serious.

Although the problem should be addressed by both prescribers and pharmacists, community pharmacists, because they are almost the sole supply of prescription medication, should be in a position to perform this function effectively and efficiently.

Any development, such as pharmacy computer medication records, which aid the identification of drug-related problems at an early stage, is to be welcomed. Computer medication records can be criticised for

not providing a complete picture, because people are free to go to any pharmacy. But in many countries people are free to go to any doctor and the medical system still functions. In practice, many people, especially elderly people and those on long-term therapy who are most at risk of these problems, do return to the same pharmacy, and little additional information other than use of the drug is required to check for an adverse drug reaction.

I would like to say a quick word about direct mailing systems. If you are thinking about the future, this is a development the pharmacy has to address. The advantages in terms of cost and efficiency of direct mailing distribution are obvious. It is no surprise that a health organisation that wants the minimum service at the cheapest price will consider it. But it is only a supply system. It is unlikely that there will be comprehensive information on consumers. The system is likely to be for long-term users, and these are often the elderly or chronically ill who are most likely to be on multiple therapy and have the greatest propensity for drug-related problems. There will be less opportunity for monitoring adverse effects. We know that the majority of people do not take their medication as intended and that in many cases this is not lack of comprehension of dose directions — that can be clarified in a leaflet, as discussed in an earlier paper. Moreover direct mailing systems run counter to the health care philosophy of the 1990s. It assumes that people are passive recipients of health care, taking their drugs as instructed, rather than being active in deciding their own health actions with the aid of professionals. Medicine and patient problems and issues should be discussed with clients and a decision not made for them.

Individuals vary in their responses to drugs, the types of problems they have, and in their concerns about them. These can only be adequately dealt with by interactive discussion — which is what I believe people want.

We do also have to address the issue of cost effectiveness in pharmacy services, though I doubt if at present we have a method that can satisfactorily assign monetary values to advising individuals. It is bound to be subjective, varying between individuals and any outcome could be the result of the interaction of many different factors. Information and discussion on prescribed drugs could be provided by the prescriber. However, GP consultations are necessarily short, people rarely think of all the questions they want to ask at the time the prescription is written. Some questions will be answered by the information that comes with the dispensed product which may be a leaflet, but this will often only increase the need for discussion, clarification, explanation, or even a second opinion about the suitability of a drug.

Professional advice is highly valued in our society. I believe that pharmacists could perform this function cost effectively. Pharmacists should

be remunerated for the advice that they give and be accountable for the quality of this advice.

In conclusion, I hope that the pharmacist's role in advising on health and medicines will become increasingly important in the future. The reality is that large numbers of people do ask pharmacists for information and advice and will continue to do so. As long as people become ill, they will want information; they will want to discuss their illness and drug therapy, *their* concerns and *their* problems.

People report that major sources of information are from the mass media; medical stories on television are very popular. This information is stylised, it may be dramatised; advertising, reports of 'wonder drugs' which often do not turn out to be so, or scandals or errors — the type of information that you would expect to make a headline. People have a right to objective information about health care and drugs, relevant to their own health concerns. Why should they have to depend on these sources?

Pharmacists or doctors do not have time for a prolonged discussion with everyone. Package inserts, whilst a definite improvement on the written information that has been provided in the past, will not answer the questions of many consumers. The level of understanding of drug and clinical issues differs greatly between individuals. Not everyone who purchases a drug will need or want advice. However, it does not mean that the service should not be available for anyone. As a general rule, the more information you give people the more questions they have. Package inserts and leaflets, which should be supplied with all products, will never be a substitute for oral discussion, but will stimulate the demand for it.

Much as I believe that the future for pharmacy could be very rewarding, I also perceive some barriers to change which could stifle developments.

Some pharmacists perhaps have a reluctance to relinquish practical tasks. They must continue to oversee the dispensing process and be satisfied high standards are maintained. But monitoring and advice about prescription drugs and increasing numbers of non-prescription products must be a central role.

The right to information is not universally accepted. There are still some professionals who doubt that people actually have a right to any information.

Some pharmacists still comment that too much information may worry the patient. I think this implies that there is something to worry about. If that is the case, the clients may like to make their own decision about it. It may be, if people do not turn to pharmacists for information, pharmacists are partly to blame.

# Audience debate

**Dr R J Chiswell** (Ciba Pharmaceuticals): As earlier papers have said, information given to patients in doctors' surgeries is poorly retained. Is there any objective comparative evidence as to the extent information given to patients in retail pharmacies is retained?

**Mrs Linda Stone:** There have been no specific studies, but there has been some work indicating that patients are more likely to retain information given to them by a pharmacist than a doctor because they are more relaxed.

**Dr Philip Brown:** I think the issue is not so much a question of whether five minutes with the doctor or seven and a half minutes with a relaxed pharmacist is going to help. The point is that you need the information at the time you are taking the product. There has been an attitude, which runs through the entire provision of information debate, and that is that somehow or other somebody else is responsible.

When you listen to advertisements for products on the radio there is always the proviso 'Ask your pharmacist'. The implication is that there is only half the message is in the patient pack insert. Consumers should take the attitude that it is 100 per cent. Once this is understood, how much information do consumers need from the pharmacist and the doctor?

**The Chairman, Lord Peston:** Without wishing to exaggerate, it is my guess that 90 per cent of what I have told my students over the years is forgotten before the lecture is over. I do not think we can blame GPs and pharmacists for the consumers lack of retention of information. It seems to me to be a standard human characteristic.

**Dr Felicity Smith:** I agree that the time the information is needed is when the product is taken. I am a strong supporter of written information being available to people at that point. However, I do not think it will answer all their problems. I think it may stimulate their need for both clarification of what is in the information leaflet, and further discussion. I think that pharmacists should be fulfilling this role.

**Mrs Diana Brahams:** To my knowledge, current practice does not require a pharmacist or a doctor to promote the least expensive medicine, whether it is on private sale or privately prescribed. So long as the doctor or the pharmacist does not mislead the patient there is no ethical or legal requirement to provide the patient with a full range of prod-

ucts, unless medical or pharmaceutical practice requires it. There does not appear to be any reason for him to promote the cheapest alternative. In fact, logically, since pharmacists are running a business there are strong reasons for him not to do this.

The difficulty is that if pharmaceutical practice requirements do not require objective advice about products to be part of good practice, then pharmacists should be honest in the way they promote their medicine.

**Mrs Linda Stone:** The first principle of the Code of Ethics is that the care and welfare of the patient is paramount. If you do anything that jeopardises that you have to defend that action to your peers.

I can put my hand on my heart and say that I have never, in all my professional life, recommended something that I do not believe to be the most effective product that I have available for the condition that is presented. If I believe that the most effective product is nothing, or a hot drink, a hot bath, or going to bed or, at the other extreme, to go to the doctor now, I will say that.

Whilst I cannot speak for all the other 19,999 community pharmacists I would say that this is the way I have always behaved and I know that many of my colleagues behave in a similar fashion.

**Dr T Medinger** (Zeneca): When I go into Tower Records up the road to buy a CD, on the desk is a copy of *The Good CD Guide,* the *Penguin Guide to Records,* and so on. Why when I walk into a pharmacy is there not the *Datasheet Compendium,* a patient information leaflet compendium, the *British National Formulary* and so on, on the desk for me to consult? If pharmacists wanted to make information available, this could all be done today.

**Mr Derek Prentice:** I entirely agree with you. Why should there not be that kind of information? I do not see why information on commonly purchased medicines should not be available to all consumers who want it. Not everyone will by any means, but it is the fact that it is available which actually changes the attitude.

The fact that pharmacists have a role is beyond doubt, but it has to be a role to provide information in a manner which the customer wants.

Many of the problems and questions consumers have, could be answered better and more conveniently, for the consumer, by having interactive media services — in pharmacies, in supermarkets, departmental stores, and even in the street. Certainly if they were in pharmacies, a pharmacist back-up would be available.

**Mrs Linda Stone:** We as pharmacists have to recognise that the information we put out for consumers has to be appropriate to their needs.

Personally, I would not put the ABPI *Datasheet Compendium* out as it is likely to confuse someone who just picked it up, but I certainly would put the leaflet compendium out.

The problem we have at the moment is if we throw so much information at them which is not geared in the right way, we will actually confuse people. If you are educated and articulate you can make the decision of what information you need yourself but, so many of the population are not in that position and are unable to make that kind of decision and, if we are not careful they will read nothing.

**The Chairman:** What is troubling me is that, between the four of you, you are not getting to grips with one thing. Whilst some of you talk about what the pharmacist actually does others talk about what the pharmacist should do. We have the complaint that 'the pharmacist is not doing what s/he should do but could do'. Others have almost implied that it was a waste of time anyway.

**Mr Brendan Barnes** (Glaxo Holdings Plc): What sort of structure do the representatives of pharmacy see in the future? The model of a profession thinly spread across a large number of retail pharmacies, each with a rather limited level of professional resource to help the consumer, seems not to fit the future needs they themselves describe.

**Dr Philip Brown:** We need to recognise that in the future we will have some form or other of managed health care. In that managed health care there has to be a proper team exercise. Communication, location-wise or whatever, between all parties involved so that the patient gets is the right treatment/medicine from the very start.

If you take the young pharmacist I mentioned earlier, actually working in the general practice, looking at the rational prescribing, helping the doctors to be consistent — then this is the service of the future. It is not the service we have now.

The future of the service is whatever the market place wants. These forces will make consumers re-evaluate the service they are getting and pharmacists the service they are providing.

I believe that the role of the professional pharmacist is one where the pharmacist and the doctor work together. You could have a situation, perhaps a long way from now, where the doctor diagnoses and the pharmacist chooses the product, measures the outcome and feeds it back to the diagnostician. To me, that is the future of pharmacy. If I say that to young pharmacists, they see that and feel it as a challenge. Equally, if I say 'Would you go out into retail pharmacy as it is today?' those same young people look worried. They know that there is a lot of change coming up, and they are seeking much firmer ground for their profes-

sionalism and also to be rewarded for the quality of education they are given.

**Mrs Linda Stone:** Changes in community pharmacy are already occurring all over the country. We now go into residential homes, into patients' homes to help them with all sorts of problems. It is an evolutionary part of community pharmacy. What Philip Brown described with his young pharmacist is not the exception. That is now very much the rule.

**Ms Anegal Hayes** (Cancerlink): Do pharmacists do anything about communicating to users of pharmacies what they can expect to receive from the service? Do they offer a sort of complaints/comments procedure for people who feel they have not received that?

**Dr Felicity Smith:** The complaints procedure that operates for community pharmacy is through the FHSA, with whom pharmacies have contractual obligations and there is a set procedure for complaints. Due to the nature of the pharmacists' contract with the FHSA it only covers dispensing services or other services for which pharmacists have a contract.

**Mrs Linda Stone:** There has been a review of the complaints procedure throughout the whole of the National Health Service, which hopefully will help to simplify the process. It is also possible to complain about a pharmacist direct to the professional governing body.

Interestingly, there are many more complaints made about the other contractors, that is the hospitals, GPs, dentists and so on.

**Ms M Allen** (National Pharmaceutical Association): For about 12 months now community pharmacists have been contractually required to have practice information leaflets which set out the range of services they provide and also give provision for complaints. So just ask your pharmacist for a leaflet.

# Patients' rights — a middle-class phenomenon?

Rabbi Julia Neuberger

I have been set an essay question. 'Patients' rights — a middle-class phenomenon?'

I have to confess to being unashamedly middle-class. I do not think I can do very much about that at this stage of my life. But there is a really interesting question here, which is that if you look at the patients' rights phenomenon, it is part of the whole consumer rights phenomenon of which we are seeing the beginnings in this country. It could be said that it started off as essentially middle-class, because of the nature of the middle-class in this society. It does not mean in any sense, however, that it is now a middle-class phenomenon or that it is unique to any one section of our society.

What it does mean is that it has been the middle classes, from whom the professionals have largely been drawn, who have felt able to challenge their fathers, mothers, sisters, brothers, aunts and uncles, and say that professionals are not always right. The idea, therefore, that one might challenge, as a user of services, the view of a professional does start off as a middle-class phenomenon — for a variety of historical reasons, which include the groups in society from whom historically our professionals have been drawn. That is worth bearing in mind when we think of the difficulty that people in our society still have in challenging the views of professionals of all kinds, and indeed the difficulty that junior professionals very often have in challenging much more senior people in their own profession. It has to do with the rather hierarchical society in which we find ourselves, when we are moving very slowly, somewhat uncomfortably, from a concept in which we still essentially see ourselves as 'subjects', people who are subjected to a whole variety of interventions being done to them — ie you get your medical care and you feel you are being done good to — towards John Major's Citizens' Charter, the idea of being genuine participants and partners in dealing with our professionals. In the use of health care services, therefore, people do feel more than they used to that they have rights; that they can ask questions; in particular that they have a right to ask that the services be provided more in a way that they would like and less in a way that suits the professionals. It has really always been thought that the services operate in the professionals' interests, rather than that of the users of services.

I use these strong words because I am, if you like, a poacher turned gamekeeper. I started off chairing the Patients Association; Katherine

Whitehorn talked me into doing it for a year and I did it for three. Now, as chair of an NHS trust, a community trust, I am entirely aware that our workforce, not deliberately, are used to a National Health Service which works to the convenience of people who work in the service and not to a service which works to the convenience of the people who use it.

You can observe that in action, all over the country and in all sorts of aspects of the service. I know the NHS rather better than I know other public services, but you can watch it and watch groups of professionals actually organising the services in their own interests. That is why so many services are operated nine-to-five or eight-to-four on weekdays, whereas many of the people who use the services are working during those hours and would be very happy to use their health care services between seven and nine in the morning and again between four and nine or ten in the evening — and indeed at weekends. These are just examples of things that you could point to and see that the original design of those services was for those who operate the services, and not those who use them.

If it is middle-class to look at that and say 'Isn't there something wrong here?' so be it, it is middle-class.

I would argue that it is much more about balance within society between people who provide public services, and people who use them. A cultural change is coming about in Britain, albeit very slowly in comparison with other countries where there are very different scenarios. We are seeing a shift, and that is enormously important.

Let me take the argument a little further and say that there is a particular problem we have with the National Health Service. It is an historical problem. I still believe, all these years on from 1948, that there is something we have not really overcome. That is, for many of our patients, particularly elderly patients, the National Health Service is the successor to the panel doctors and to health care for the poor. It is bizarre to be saying that in 1994, but anybody who works a great deal with the very elderly, and in particular the working-class elderly, will be well aware that this is a particular problem. Many of our users of services still feel that they do not have rights. They feel that it is a generous act on the part of a health professional to do things for them. They also feel that it is a proper thing to have to sit and wait. It is, if you like, a description of normality.

We have to take that on board when we look at the question of patients' rights, and indeed patients' rights to information of a whole variety of kinds. Unless you think about that and that elderly tranche of the population, who after all use our services very heavily, you do not get the picture of quite why people find it difficult to make demands of the service. It is historical. Many people feel they should not be making

demands of the service. The doctors are so desperately busy; the nurses are so terribly overworked. They do not think about the pharmacists very often, I have to say! But the doctors and nurses they are quite clear about. They should not make more demands of the service. There is a pre-1948 attitude there that we, who provide health services, have to overcome.

That is the scenario in which we have to look at patients' rights. The patients' rights movement is relatively modern in Britain. We look at other societies. We look at the Scandinavian countries, where the assumption is that information is provided unless there is a very good reason why it should not be. In the United States you have a different assumption. Obviously a lot of people do not get health care at all. But you have an assumption, as a user of services in the United States, that you are entitled to everything — including the things that might not do you any good. A very, very different view from the British one. Those are two very different societies where you can see a view that says 'as a patient, as a citizen, I have specific rights'. We have not grown that view in this country yet, not fully. I hope we do. When one talks about patients' rights, therefore, one is talking about a relatively recent sense, with the younger section of our population feeling that they do have rights and the ability to make demands of our services. Those of us who run services are fully aware, for instance, that people feel more able to complain than before. You can monitor the sense in which people feel they have rights that they can demand of a service by the extent to which they are willing to complain. They do complain. Staff still find complaints terribly threatening, but there is something very useful that one can do with complaints. One can use them to change services. Because the users of our services feel that they do have rights, we now have an increased level of complaints in the National Health Service. It does not necessarily mean increased dissatisfaction.

We have a Patients Association which is one of the early patients' rights movements. This was the beginning of trying to get the idea of patients' rights — patients' representation — into the system.

We have Community Health Councils. It is worth putting on record, however, that the Government in its health reforms was considering not renewing the statutory duties of Community Health Councils in *Working for Patients*. There was some thinking that perhaps Community Health Councils were not necessary. But Community Health Councils are here to stay. They have a statutory duty to represent the views of users of health services. This is in some way evidence of a sense of patients' rights in our society.

It is all relatively recent and all rather low-key. The other group one ought to cite as an example of patients' rights-type thinking in our society are the single disease associations and the single grouping associa-

tions, who have been very effective at representing the interests of particular groups, and indeed have argued for the rights of particular groups.

We are not fully 'consumerised' in Britain and we have a long way to go. There is still an instinct in our professional groups that goes precisely against the idea of patient rights. I am certainly aware, as someone who serves on the General Medical Council, that although lay members are in one way regarded as very welcome and very much 'people we ought to have here as the users', there is a feeling that we could be awfully difficult — and of course we can. There is a feeling these days, because we have changed everything, that we ought to have users' representatives in a whole variety of ways. But what we want to breed in Britain is the 'tame' user rather than the user who will say what is actually wrong with the service, the professional group, or whatever. I try to say difficult things very politely. I sometimes fail.

Let me take it a little further. If I say we have it on the agenda, but on the agenda gently, I mean that. We have patients' rights on the agenda, but it is pretty slow.

Look at the Patients' Charter. Although many health professionals have been very rude about it, I happen to think is enormously important. It puts down huge markers and sets targets for health professionals and health service managers about providing services. For instance, that waiting areas have to be of a reasonably high standard. It may seem very unimportant and you hear doctors huffing and puffing, saying 'What does the waiting area matter?' They do not sit there for three hours! We are putting down a marker, saying the quality of the accommodation in which people sit who are waiting for services matters, because we actually think that users of services are our social equals. I think that is really important.

Similarly, the issue of waiting times. Again, you will frequently hear health professionals saying 'Why are we banging on so often about waiting times?' If we have within the Patients Charter, as we do, targets on waiting times, it certainly concentrates the minds of health service managers and certainly stops clinicians booking in a great number of patients all at the same time, because they regard their time as more important than the patient's time.

If you want to look at where it makes a difference, it is in the thinking. No, it does not give the patients all the information they need in the Patients' Charter. No, it is not a crusade for patients' rights. We are a long way from that. But it is a marker; it does change the agenda. Thus far, it has been hugely important.

Moving on in that area to the question of league tables for hospitals, which I know make many health service professionals shrink and glower and get terribly upset, I have to say, as someone who comes from the

patients' rights movement and who is now a provider, I am fully in favour of league tables. It is very hard for members of the public to judge the quality of the services they receive. It is quite clear that members of the public often prefer a good bedside manner to a bad bedside manner. No reason why they should not. It seems perfectly reasonable to me. But if you can publish information showing comparative mortality data, however much you have to adjust them for case mix and so on, and however crude those data are, I believe it will concentrate the minds of clinicians and health service managers; I believe people will be more prepared in the audit process to say to people who are not performing well 'Hang on a minute, didn't you make a mistake here? Shouldn't you perhaps have some further training here?' or whatever it might be. It is a very uncomfortable thing to say, but I believe that patients have the right to know about comparative mortality data from one hospital to another. It is not only about waiting times any more.

I would argue that it is extremely important to use people who know about the giving of information, in providing information to consumers of services, to patients. Some years ago, I carried out a piece of research (Neuberger, 1992) looking at research ethics committees in the United Kingdom; ie where the research ethics committee would look at a piece of research to be conducted on human subjects and look at the information sheet to be given to the patients recruited into a particular trial. What was most interesting to me as I went round the country as an observer, looking at them in operation, was that it was usually the lay members of these committees who would look at the patient information and say 'Nobody can understand that!' and send it back. One of the ways you can test out patient information is by trying it out on some patients; not necessarily the individual patients who will use it, but a group of patients. We have been too slow in this country in drawing together focus groups who can look at information, actually involving people who are likely users of that kind of information, and saying whether or not the information is good enough; whether they can understand it; testing it out on people with different reading age levels; testing it out on different groups in our society.

We have been extraordinarily slow. The professionals have tended to say that they know what information ought to be given; they know about the risks that ought to be warned of. They may well do that, but they do not necessarily convey it very well. One of the ways to check whether you have conveyed your message well is to ask the people to whom it is directed. It is possible. In the area of research where ethics committees play an important role in balancing patients' rights with medical progress, it has been lay people — and, I should add, the nursing profession — who have taken the lead in saying, when information is circulated, 'This information for patients will not do. People will not

understand it. I don't understand it'. In case you think that is a middle-class phenomenon — because there is a dinner-table method of recruiting people to research ethics committees — the most impressive lay member of a research ethics committee I ever saw was a policeman, who was anything but middle-class. He would sit there and make every senior consultant shake in his shoes! He just said 'What are you talking about? What is this about? I don't understand. If you can't explain it so that I understand, they won't understand it. You can't do it'.

It is very basic, but it is a kind of acid test. If you cannot get people to check it, to see whether they can understand it, it is not any good. You have to check that it is understood by the sorts of people who are likely to look at it. As we have a very mixed population in this country and we have a lot of people who do not have English as their first language, you have to check language availability for all sorts of information; that you can produce some information in terms of video; some information graphically, and again you have to check it out with the groups of people who will use that information. If that is not done, I do not believe the people who are in the information-giving business were even serious about it in the first place. I feel very strongly about it, because there seems to me to be something that is either lazy or arrogant in saying 'We have the expertise. Why do we need to check with the people who need the information?'

I will now pay a compliment to pharmacists. They may feel a bit shocked by that! Where we do have community pharmacists working closely with particular communities, it is quite clear that pharmacists, talking particularly to people with language difficulties about adverse drug reactions, have been remarkably effective. There is a role for particular professionals, therefore, working with particular user groups where there may be a difficulty over understanding. Again, it is in that relationship where people are checking both ways, where people understand. Do the users understand what the professionals are saying? Do the professionals understand what the users are saying? Is either side really listening? You can only do that by testing it from time to time.

I want to end with some examples where the patients' rights movement has had some notable successes. In the end, whoever started it — be it middle-class, be it working-class, whoever, even the professionals who thought they might have some noisier users, and there were quite a lot of those in the early days — there have been some signal successes of the patients' right movement, which show we can grow a proper and responsible user and consumer movement in this country.

I will give you four examples, but there are many others I could cite. The first example is utterly middle-class. The area of choice in childbirth. It started off very much from a group of largely middle-class mothers, saying 'What is all this medicalisation of childbirth? Why are

you telling me I have to do it this way? There is no reason in the world why I should not do it that way, or some other way altogether'. As a result of a users' movement in the field of childbirth, almost everywhere throughout the UK women are offered choice in childbirth — including, although very often with great difficulty and against medical professional feeling, the option of having a baby at home. That is quite significant. In some ways you could say that the consumer movement has won; that, although many obstetricians really disapprove of home births, that choice is offered to a lot of women. Women have made it clear that in normal births there is, looking at the data, no greater evidence for more problems with home births than any other kind of birth.

The second area I would cite, because it is not at all middle-class, is that of breast cancer. There has been a very significant change in the way that women have been treated as a result of brave patients taking issue with their health care professionals and, very particularly, with the surgeons and the general surgeons concerned. In the 1970s and the early 1980s, there was a series of complaints, some of them deeply distressing, some where research was carried out on women without their knowledge or consent. As a result of an extended campaign by groups of women patients of all classes, in most cases of breast cancer, women are now offered a choice of treatment. If they have non-nodal involvement primary breast cancer, they are normally offered a choice between mastectomy and lumpectomy and no pressure is brought to bear on them. This would not have happened without an effective patients' rights movement in this area. However, the patients' rights movement has considerable work to do in this area, given all the figures we have been seeing about variation in outcome in women with breast cancer, depending where in the country you are and by whom you are treated. That is the next agenda for the patients' rights movement: to say 'This will not do. I am not having my treatment here'.

The third area which the patients' rights movement-type work has had enormous success is in the field of HIV and AIDS, where there is a very vocal, articulate and young group of seriously ill people. They have been enormously effective in campaigning for resources, in refusing to undergo research unless they could have access to what seemed to be a possible 'miracle drug' for them — and that certainly drove all the scientists mad! They said 'We cannot randomise a controlled trial' and the people who had AIDS said 'Up yours! We would rather have a chance of having the drug'.

You do have to say that there is a balance of interest here. It is very hard to judge. Many of us may disapprove of what actually happened. Certainly in terms of the patients' rights movement being effective, however, people with AIDS and HIV in the late 1980s and early 1990s were enormously effective in changing the agenda. I believe, although

the decision in some of those cases may not have been right, changing the agenda was hugely important and has changed the way we think.

The last and perhaps the most difficult area has been in the field of mental health. There, in some very limited areas, we have seen the growth of patients' councils in in-patient mental health units. Those patients' councils used merely to discuss very minor things, such as whether they could have clean sheets more often, et cetera. Increasingly those patients' councils have been talking about recognition of cultural variation, acquiring the sort of food within those units that reflects the cultural diversity and they have, in alliance with health service managers, talked to the doctors about the way that drugs are given, and the dosages of drugs they receive.

That has been one of the most interesting developments. It is very much in its infancy, but, as a result of seeing the successes of other patients' groups, we now have a very large group of people with severe mental health problems also believing that they have rights and that they can sometimes challenge the professionals.

I do not care where it comes from, therefore. Middle-class or not, I want to see the patients' rights movement thrive and a proper partnership between professional groups and patients' groups, each side asking questions of the other and making sure that the other understands.

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