

6. Information for patients

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All over the world, governments are pressing the notion that health is an individual responsibility. The public, patients and carers are being urged to learn about preventive care and to use informal support except when health services are essential¹. In the UK, the National Health Service invested heavily in the freephone Health Information Service, and this was rapidly eclipsed by NHS Direct. Many drugs have undergone transition from licensed to over-the-counter use; and a new initiative, UK Online, provides government information in a manner designed for the needs of the citizen—for example, a website focused on life episodes such as having a baby. The motive is citizen empowerment, and the aim is not just to inform patients and carers but also to engage them in health decisions.

This global trend coincides with a remarkable growth of technologies for communicating with the public. For example, 37% of the UK public already have access to the web, and the figure will be 50% by the end of 2000. Over 20 million mobile phones in the UK can already receive SMS text messages, and third-generation mobile Internet phones will replace the restricted WAP phones. The Government has put money into development of health applications for interactive digital TV; and patient-held records, being considered as part of the NHS modernization agenda, could also increase the demand for health knowledge.

However, different people have different coping styles. Some patients want to know everything and express strong opinions on the choice of procedure or possible outcomes; others are happier not knowing the full facts, preferring to leave the decisions to their doctor. Although, in a consultation, individual coping strategies must be taken into account, in general we can predict several benefits from giving patients greater access to clinical knowledge. First, it may reduce anxiety, particularly if the patient or carer has a misconception that we can correct. Second, understanding of risk factors, preventive care or self care (such as how to recognize when things are getting worse) may lead to less disease, earlier presentation of disease or more appropriate use of health services. Third, information

may improve a patient's appointment-keeping and adherence to therapy. For example, one study revealed that twice as many discharged patients knew about their drugs and brought them to follow-up appointments when they were given an information leaflet about their therapy². However, a systematic review³ of 13 randomized trials indicates that information alone does not improve adherence; it has to be part of a package of measures. Finally, shared decision-making ought to make professional practice more interesting, lead to better tailoring of management to individual patient preferences, and improve health outcomes.

INFORMING THE PUBLIC OR PATIENTS

Three broad methods for informing the public are:

- Decision aids, which provide individual patients with information about their symptoms, drugs, or the options they face; these may also contain information on the disease and probabilities of alternative outcomes
- Planned mass media campaigns targeted at groups, not individuals
- Uncoordinated media coverage of topical health issues.

Sometimes patient information can be very effective. For example, in a small Danish randomized trial, patients who were told that their chronic chest complaint was 'smoker's lung' were twice as likely as controls to have stopped smoking one year later⁴. In another randomized study, a leaflet informing patients about the aetiology and natural course of viral upper respiratory tract infections significantly reduced general practice reattendance rates⁵. A systematic review identified 17 randomized trials of such individual patient decision aids⁶. Overall, the information produced better knowledge of options and outcomes, lower conflict scores and more active patient participation in decisions, without an increase in anxiety (but also without an increase in satisfaction with the decisions). The extra information had a variable effect on patients' decisions, ranging from a 26% reduction in willingness to undergo major surgery to no effect on decisions about screening tests or circumcision of a baby son. Complex decision support tools such as computer-based multimedia or video were only slightly better at reducing decisional conflict and led to

slightly higher knowledge scores than simpler ones. This is consistent with work now underway in Cardiff showing that, for decision-making about hormone replacement therapy, asthma and fetal screening for Down's syndrome, video is no better than a well-designed patient information leaflet based on the video transcript (Wright P, personal communication).

What about mass media? A Cochrane systematic review found no randomized trials but identified 17 rigorous time-series studies of effects of mass media on health service utilization⁷. 14 were studies of formal media campaigns lasting from 1 week to 4 years, while the remaining three studied unplanned media coverage of specific health issues. 16 of the studies were reported as positive but reanalysis showed that only 7 demonstrated a statistically significant impact on health service utilization. The overall impact of the 14 planned campaigns on health service utilization was a 54% change in the intended direction (either reduction of inappropriate use or increase in underused services), while unplanned media coverage led to a 24% change, about half as effective. The effectiveness also varied according to the kind of health service utilization targeted, with a 96% increase in immunization rates (pooled results from two studies), a 12% increase in cancer screening (seven studies), a 42% increase in HIV testing (three studies) and a 45% increase in the use of emergency services for myocardial infarction (two studies).

Potential drawbacks of informing patients

Some clinicians declare that 'a little learning is a dang'rous thing', expressing concerns that include:

- Creating a nation of worried well or 'cyberchondriacs'
- Dehumanizing the doctor-patient relationship by shifting information-giving from the clinical encounter to telephone or Internet
- Prolonging clinical encounters because patients have more questions, and doctors may need to counter Internet-borne rumours
- Information providers trying to manipulate the public to suit their own ends.

Arguments against these propositions are that patients with chronic diseases have more time and motivation than anyone else to inform themselves about their condition. In middle-class areas one in six patients has either trained in a health profession or has a close relative who has trained, so may expect detailed information. The last point, about manipulation, may be true, but most people know they should be sceptical about product claims.

There does exist a strong desire for information. In a survey of 250 cancer patients, 80% wanted as much

information as possible; 96% wanted to know if they had cancer and 91% the chance of cure⁸. Women, patients younger than 65, patients treated radically and those from more affluent areas were more likely to want information about possible treatment options.

Thus, the aim must now be to push ahead while doing our best to limit the drawbacks.

WHAT DO PATIENTS WANT TO KNOW?

There is a huge range of information that people might wish to have—ranging from 'I wonder if I should lose weight' to the harrowing 'Should I let this surgeon correct my baby's transposition?'. This series of articles concerns health knowledge so we will not discuss here the question of providing public access to professional performance data, though the NHS Information Strategy asserts the importance of this⁹. Nor will we consider information about the NHS (e.g. where is the nearest dermatology clinic?), obtaining contact details or getting support (I'd like to talk to someone else with psoriasis).

With its low cost and widely known telephone number, the NHS Direct helpline provides excellent insights into the kind of health questions to which the public want answers. Analysis and coding of transcripts of 267 randomly selected calls from June 1999 revealed that the main topic was patient complaints or symptoms in 72%, diagnoses or diseases in 22%, diagnostic, screening or preventive procedures in 5% and medication or treatment in 1%¹⁰. The calls were further classified by the body system concerned—see Table 1.

One surprise was the rarity of requests for information about circulatory troubles; this may reflect public preconceptions about the urgency of such disorders or the role of NHS Direct.

WHERE DO PATIENTS CURRENTLY GO FOR INFORMATION?

It is hard to know exactly where patients learn what they know about health. Pupils are taught about personal health at school, people buy 'home doctor' books, and there are daily health programmes on radio and TV and articles in newspapers and magazines. The 1990s saw the advent of whole magazines devoted to men's health. However, the impact of these media on the public's knowledge of the structure and function of the body is unclear. In one study, 65% of surgical patients gave completely wrong answers about the function of internal organs and 58% placed organs in the wrong position on a body chart¹¹. Presumably, their knowledge about abnormal function was even more sketchy.

One contemporary indication of where people turn for health advice is a survey of 15 000 randomly selected people in the catchment areas of the three first-wave NHS Direct

Table 1 Main topic of 267 randomly selected calls to NHSDirect, June 1999, classified by body system.

Data from Munro (Ref 10)

Classification	%
Unspecified	20
Digestive	17
Musculoskeletal	15
Skin	14
Respiratory	9
Neurological	8
Eye	4
Ear	2.3
Social problem	2.3
Male genital	2
Urological	1.5
Circulatory	1
Psychological	1
Endocrine/metabolic/nutrition	1
Pregnancy, family planning	0.8
Female genital	0.8

sites conducted just before the helpline was set up in 1998 and repeated one year later¹⁰. Responses came from 70% with features typical of the UK adult population. In the 4 weeks before the survey, 38% of respondents had sought help or advice for a health problem (unchanged after NHSDirect was implemented). Figure 1 shows the overall rates of unplanned use of the main sources of health advice or treatment.

After GPs (17%) and high-street chemists (total 12%), family or friends (11%) are the commonest single source, with all others accounting together for only 12%. However, if family and friends use the Internet, this may become an equally useful way to reach patients.

KEY ISSUES RELEVANT TO PATIENT INFORMATION

Quality

One major concern with certain media, especially Internet websites, is the variable quality of information, which may be incomplete, badly organized or inaccurate¹²; such deficiencies can have serious consequences¹³. This leads on to how doctors should respond when a patient offers a web printout. A check on the date of preparation, sources used, qualifications of the author and who is sponsoring the site should help to establish the likely accuracy of the information presented. Looking for a quality label such as that issued by Health on the Net foundation (www.hon.ch)

may help separate wheat from chaff. Some websites act as portals, appraising other sites according to explicit criteria; OMNI is an excellent example (www.omni.ac.uk). The Discern checklist helps in the scoring of how closely material is based on evidence—but few sources do well on this score (www.discern.org). The NHSDirect online site (www.nhsdirect.nhs.uk) uses this approach but also provides other material which does not yet approach the Discern standard; it is very popular, with about 100 000 hits a day. Finally, patients can be referred to an excellent website that logs quackery: www.quackwatch.com.

Choosing appropriate media

We tend to think of patient information as leaflets, but a key issue is to avoid social exclusion and enhance accessibility. Thus, information may need to be translated to other languages and made available in alternative media—including audiotapes (such as the College of Health phone lines) or videotape for those with limited reading skills (up to a quarter of the adult population), large print for visually impaired people and Braille for deaf-blind people¹⁴. Brevity, visually attractiveness and simplicity are also key elements. Public kiosks that allow privacy but make information available in shopping centres or libraries have a clear role, but can be bulky and expensive and need to be further evaluated. Some patients or carers are so bewildered they do not even know where to start. A charity called Start Here acts as a pathfinder to this group.

Assessing readability

The best way to assess readability is to ask patients for their opinions; for research purposes this can be quantified by getting them to fill in missing words in material they have

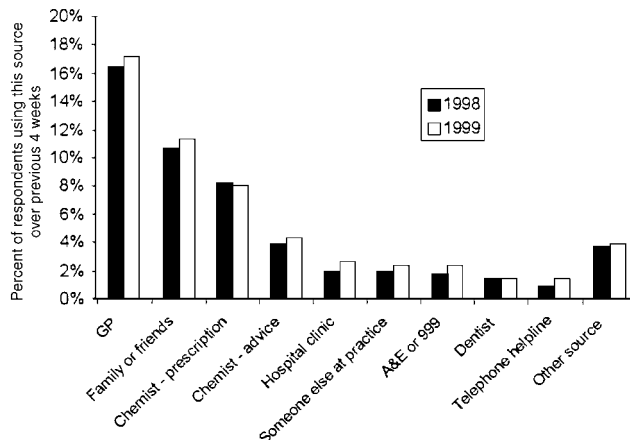


Figure 1 Sources of unplanned advice or treatment in people in catchment areas of first-wave NHSDirect sites. Data from Munro (Ref 10)

Box 1 Effective writing for patients (adapted from Ref. 15)

Place the most important information first or last
 Write in a conversational style with short words and sentences
 Limit each paragraph to a single message
 Focus on specific personal experiences rather than generalities
 Ensure that the use of words is consistent
 Use headers to alert readers to what is coming
 Cut out irrelevant information
 In general, write in positive sentences
 Use negative sentences when advising patients to avoid actions
 Ask patients to read your draft and to suggest how to improve it

previously read—the Cloze technique¹⁵. Computed readability measures such as the Gunning Fogg index (accessible under document statistics in some wordprocessors) can be a useful guide but may not be accurate, particularly in chronic diseases where patients become familiar with medical jargon¹⁵. The ultimate test of patient materials is their impact on actual patient decisions, actions and outcomes, but few studies have been performed¹⁶.

Improving readability

No medium will be effective unless patients can readily find and interpret the information it contains. Mayberry *et al.* have summarized ‘information design’ principles based on sound empirical findings¹⁷, in their paper on effective writing for patients¹⁵—see Box 1.

One particular difficulty in communicating with the public concerns the matter of risk—as politicians know to their cost. A classic example is the 1995 media scare about the doubling of venous thromboembolism rates with third-generation oral contraceptives, which led to a substantial rise in unplanned pregnancies. Had the rarity of the side-effect (the baseline rate was only 75 per million) and the high proportion of women not developing it (99.99%) been emphasized, it is doubtful that the public would have overreacted in this way. Thus, the language used to communicate risk to the press or public requires scrupulous attention.

Avoiding unnecessary complexity

The cost of multimedia or video is rarely justified except to address specific impairments—because, as I pointed out earlier, they seem no better at informing or alleviating anxiety than a well-designed printed leaflet with the same content. An example of this is a trial comparing uptake of fetal anomaly scans in antenatal patients exposed to a sophisticated touch-screen computer system costing £25 000, or a leaflet, in a Scottish clinic: the scan rate was only 7% higher in the touch-screen group¹⁸. Equally,

there is interest in tailoring information to the individual by asking the patient some questions first or linking to electronic patient records. While elegantly tailored smoking-cessation and other leaflets can be generated, their contribution to better informed patient choice is unclear.

CONCLUSIONS

At present we do not involve patients sufficiently in decisions about their own health. An exhaustive study of 1057 taped encounters with 59 US primary-care physicians and 65 surgeons showed that only 9% of the decisions were adequately informed, even though the average encounter lasted 16.5 minutes, double that in the UK¹⁹. Although surgical encounters were 3 minutes shorter, those decisions were better informed, so lack of time may not be the issue.

Communication about health with patients and the public is a growth industry, and the medical profession should engage in it. There are some good materials available and we should always strive to avoid reinvention; however, when the quality of existing material is imperfect, the best solution may be to write our own—perhaps with the aid of someone familiar with writing for the public, for example a friendly journalist, and patients themselves. Modern technology can also help: the half-empty rack of dog-eared leaflets in our surgery could be replaced by new printouts from an evidence-based website such as www.patient.co.uk (which, despite its commercial sounding title, is run by two Newcastle GPs). This avoids the need for stock control, and we can even e-mail patients with a pointer to the website, allowing them to check for updates themselves. This is a perfect way to respond to the increasing number of patient e-mail requests for information²⁰.

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