

# The Art of Communication

Patient information is very often a neglected area, leading to low rates of recruitment and compliance in clinical trials, and incorrect medicines usage. Involving medical communication specialists can help facilitate a broader understanding

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I am very fortunate in my role as a strategic medical writer – clients who recognise that I've been doing this for longer than it would be polite to admit often ask for my opinion, rather than just give me a set of instructions and tell me to churn out a document. However, what never ceases to amaze me is that while discussions of regulatory strategy can certainly become heated, this is nothing compared with the extremes of reaction seen in discussions about patient information. The most frequently encountered reaction to communicating patient information is apathy, and there are many possible reasons for this. The most usual is that patient information is seen as 'nothing special', and something that 'anyone can write'.

The task of 'writing something to go with' a drug or device is frequently given to anyone who has the time or vague inclination. When a medical writer is finally approached for help with the situation, explaining to clients why their leaflet has failed its readability test, or why their 'Dear Doctor' letters or sales training are not achieving the desired results, is sometimes met with a mixture of irritation and bemusement. This is all understandable, however it raises an interesting point: why

is a lot of patient information so poorly communicated, and what are the implications?

## Consequences of Low Health Literacy

Health literacy can be defined as the ability to obtain, process and understand the basic health information and services needed to make appropriate health decisions and follow instructions for treatment (1). There is certainly no doubt that health literacy and numeracy have a huge impact on patient engagement, compliance and health outcomes. However, this is not affected only by an individual's general ability to read, write, and understand text and numbers, and certainly not just by their overall intelligence. An individual's experience of the healthcare system, the complexity of the information being presented, how the material is being presented or explained, and cultural factors (that may influence how decisions are made) all affect the level of 'health literacy' or 'numeracy' of any individual at any given time.

The quality of patient information is particularly important in the clinical trial setting. When new drugs or procedures are being investigated,

patient understanding of the potential benefits and risks of their involvement is paramount. Poor patient information can lead to both reluctance to join a trial and low compliance levels during it.

Additionally, the increasing influence of patient groups should not be underestimated. The European Patients' Forum has called for patient group involvement in healthcare policy decisions, and Patient View was formed in 2000 to gather together, work with, and study worldwide non-governmental health organisations (including disability groups, carers' groups and gender-based groups). The organisation is growing continually in numbers and scale of influence, and conducted a survey that ranked the top 30 pharma companies on six indicators, one of which was 'the quality of the information for patients which it provides.'

Patients' failure to take medicines properly is a growing problem, and is very common – 50 per cent of people don't take their medications as prescribed, and this is responsible for 10 per cent of all hospitalisations and over 125,000 deaths per year in the cardiovascular area alone (2). Shockingly, approximately 10 per cent of adverse drug reactions

can be attributed to a communication failure between provider and patient (3). Low health literacy is associated with poorer health outcomes and poorer use of healthcare services. It is significantly associated with higher all-cause mortality, and in the US it is estimated to cost \$106-236 billion per year (4,5).

### Standards of Public Literacy

So how severe is the problem of poor health literacy? In a recent study of adults presenting to an average city emergency department in the US, 15.5 per cent had limited health literacy, which was associated with various factors including increasing age, male sex, non-English first language, non-white ethnicity, limited education, and unstable housing (6). There is limited information on levels of health literacy in England. However, the Skills for Life Survey showed that 1.1 million people in England were functionally illiterate, and approximately 16 per cent of adults have lower literacy skills than those of an average 11 year old (7). The figures are even worse for numeracy, with 1.7 million people being functionally innumerate, and it is known that people with a lower numeracy level make larger errors in interpreting medicines' side effect risk information. Therefore it is very likely that for many people, low health literacy acts as a significant barrier to achieving and maintaining good health.

The need for effective communication is especially important in vulnerable groups such as the elderly or paediatric populations. The elderly population is increasing – there will be around 72 million individuals aged at least 65 in the US in 2030, compared with 38.6 million in 2010 – and there are increasing numbers of individuals with dementia (8,9). Poor reading skills are particularly problematic in the elderly because of a high prevalence of chronic disease and their need to understand

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healthcare information; often their diseases have complex treatment regimens, and require multiple consultations with different clinicians. Adherence to medicines by children and young people is even worse than that of adults, despite the oversight of parents (10).

Tackling the problem of poor patient information has its own challenges. We live in an increasingly information-rich environment, and patients are one of the most information-hungry subsections. A Medicines and Healthcare Products Regulatory Agency (MHRA) survey in 2005 showed that people want more information about medicines, and that they value the patient information leaflet more than any other source, except for doctors and pharmacists. Unfortunately, they do not always understand the patient information they receive. Studies have consistently shown that patient education leaflets are written at an excessively high reading level. One survey showed that almost a third of patients did not understand instructions on their medicine label and in a UK outpatients study of chronic obstructive pulmonary disease (COPD) patients, 15 per cent were not able to use the written information they had been given (11,12).

As society becomes increasingly technologically aware, patients are turning to the internet for health information: 80 per cent of internet

users look for health information online and a survey of 178 cancer listserv users showed that 35 per cent chose the internet as their preferred source of health information (13). Given that well-known studies show that patients recall less than 50 per cent of what they are told during their consultations it is perhaps understandable that patients would turn to the internet for further information or explanation (14,15).

Unfortunately, not only are there myriad uncontrolled and unreviewed sites available, but the internet does not necessarily offer more easily understandable healthcare information – even on reputable sites. For example, information on breast cancer prevention obtained from the National Cancer Institute's website has been assessed as being written at far too high a level, and there is marked variation in the quality of available patient information on websites about the treatment options for Crohn's disease and ulcerative colitis, few of which provide high quality information (16,17).

There is no doubt that patient information is important, and high quality information can make a hugely positive impact. It has been shown that patients who received specific pre-operative information on the procedure and written instructions on post-operative care experienced less pain, consumed fewer analgesics and had a swifter return to daily activities (18).

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### Providing Patient Information Effectively

So what can be done to improve the degree of health literacy in patient information? The documents need to be written for the right audience. This means taking into account what the reader wants to know, what they need to know, and what they might know already. Patients prioritise four key points of information when they are reading about medicines: the side effects they might experience; what to do and what not to do; what the medicine does; and how they should take it. The medical writer’s job is to provide this information in a format the patient can understand and access as easily as possible. While this might sound straightforward, it is often far from simple, particularly considering that English might not be the first language of the reader, or that they might be affected by mental or visual impairment, or might not be able to read at all (necessitating the careful use of visuals). It takes experience and skill to identify potential hurdles to understanding, let alone to counter them, but there are some general guidelines that can help along the way.

To be effective, patient information should focus on eliciting key behaviours from the patient – taking a tablet at the right time, with food – not lengthy and unnecessary detail about biochemistry and pathology. Yet many patient leaflets begin with a lengthy discussion of the disease area

or physiology, instead of explaining to the patient what they need to do and why.

There are a number of techniques which can be employed to make documents more ‘patient friendly’, such as style and formatting changes, sentence structure, and grammar and vocabulary considerations. Information should be given with short words and short sentences, and only essential information should be included. Long or unfamiliar words are often difficult to understand, and they slow down reading speed. Content should be limited to one or two key objectives, and should be appropriate for the age and culture of the target audience.

The average reading ability of the general public means that text should be written at or below the level of a 12-year-old, short paragraphs and the active voice should be used. Humans have a cognitive preference for picture-based information, and research has shown that using pictures, including cartoons or pictographs with verbal explanations and use of models, can greatly increase patient understanding and retention of information. In one study, the mean of correct recall of information was 85 per cent with pictographs and 14 per cent without (19). Another study found that patients receiving wound care instructions with cartoons were able to answer questions correctly 46 per cent of the time three days later, compared

to only six per cent of patients who received only written instructions (20). However, this should be used with caution, as leaflets that become too ‘cartoon-like’ can be perceived as patronising by adults, and all images should be age and culture-sensitive. Readers will very rarely put effort into trying to decipher what a sentence or paragraph means – they just skim-read it and move on. If the message can’t be gleaned from a quick skim of the text, they will miss the point and the information leaflet is wasted.

### Target Audience

Using tools such as these can lead to more effective communication with patients and thus higher rates of recruitment, retention and compliance in clinical trials, and lower incidence of side effects, and more effective use of medicines. However, there is also a certain amount of knowledge and expertise needed to refine the documents even further, and to maximise the effectiveness of the document for its intended audience. Once they have written the text, good medical writers will check it for ‘readability’, although care should be taken. For example, one well-known tool for readability is the Flesch-Kincaid readability score – a useful guide for measuring how complex a piece of text is – but it has drawbacks. The score is based primarily on word and sentence length without considering content or vocabulary. For example, the sentences ‘cat hat is big sat on a mat. Fox stared mouse nose big hat’ have a Flesch readability ease score of 100 (the highest possible), showing that they are very easy to read. However, they are total nonsense and impossible to understand.

Therefore, it is useful to have patient materials reviewed by people as close to the target audience as possible – ideally patients with limited literacy skills – to ensure that information can be understood and interpreted correctly in the format that it has been written. The Commission on Human Medicines Expert Advisory Group on Patient

Information was convened from 2006 to 2009 to work on improvements to medicines information for patients, at both a national and European level, and in 2005 the European Commission introduced a requirement for pharmaceutical companies to undertake 'consultations with target patient groups' to ensure that patient information leaflets were usable and understandable for patients (21). The Commission's guidance included a recommendation for user testing of patient information leaflets, and this testing is now normal in the EU. User testing involves one-to-one interviews with potential users of a medicine to determine whether they can find and understand key pieces of information in the patient information leaflet (22).

The particular needs of specific groups are also being addressed. Children and young people often feel excluded from discussions about medicines, especially regarding side effects, but in the UK a patient information leaflet has been produced for children and young people by a pharmaceutical company in consultation with the University of Leeds and Luto Research Ltd. This leaflet contains an extra section entitled 'information for children and young people', and all the sections are written as though the child or young person taking the medicine is reading them.

Low health literacy is a recognised issue in healthcare communications. However, instead of trying to identify vulnerable groups with particularly low health literacy or numeracy, which can be a difficult and often demeaning process for the participants, wouldn't it be more sensible to make the information understandable and accessible by all? This is not 'dumbing down' patient (or doctor, or medical sales training) information. Instead, it is creating written information in a form that all readers prefer.

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