

CME Article

The informed patient

Tovey D

INTRODUCTION

“I looked it up on Google and...” If one is to believe what one hears, it would be hard to envisage a phrase more likely to dampen the heart of any physician than this. The patient clutching a handful of computer printouts, marching into the clinic, all guns blazing, has become a contemporary cliché, along with the consequent “heartsink” experienced by the doctor⁽¹⁾.

What is it about this interchange that is so alarming? One possibility is that this is an issue of authority and power. By grabbing the initiative, perhaps the patient is usurping the doctor’s historical role as the provider of information? Another possibility is that the doctor assumes that whatever the Google search engine has thrown up, it will surely be inappropriate, biased or corrupting, or all three.

Over the same period that the internet has become increasingly available, so arguably, the clinical interaction has also become more sophisticated and complex. Other societal factors, aside from information technology, have also contributed to this situation⁽²⁾. In this environment, there is a growing consensus backed by evidence, that improving partnership working between clinicians and patients can lead to improved healthcare outcomes⁽³⁾.

In this review, I aim to explore some of the issues identified by the growth of the internet and describe some products and services that seek to support both clinicians and patients in finding evidence-based solutions to clinical problems.

UNDERMINING THE AUTHORITY OF THE DOCTOR

Let us start with the first potential obstacle, the threat to medical authority. The idea that medical knowledge is the sole property of professionals is hopelessly outdated. Even before the internet imposed itself on medical life, how frequently have had patients started a consultation with “Sorry to bother you doctor, but my neighbour/husband/employer told me I ought to see you. He/she says...”? Secondary

sources of assumed knowledge have always been present, and one might therefore ask what is so different about the new electronic scene setters? The sensible clinician has always taken seriously these second-hand reports, been prepared to examine them up closely, rather than dismissing them out of hand.

Professor Per Fugelli in his exploration of the factors that increase trust in doctors, lists sharing power alongside moral integrity, personal doctoring, compassion, competence, and realism⁽⁴⁾. Sharing power has undoubtedly become more important over the past decades, as society becomes more questioning of professionals, and more “customer-focused”. The internet has surely played a prominent part in this process⁽⁵⁾. Where it was once possible to characterise the medical consultation as being a “meeting between experts” where the clinician brought technical expertise and the patient merely his/her own experience, the internet has enabled patients to bring clinical knowledge, challenging the ground previously held by professionals.

Many doctors are chary of shared decision making, especially if they lack confidence about their own knowledge⁽⁶⁾. They may also feel that “doctor-strength” information will only confuse patients. An examination of the use of medications by people with chronic conditions provides some explanation of why patient understanding of treatment goals is so crucial. Between one-third and one-half of medicines are not taken as directed and one in five prescribed medications are never even opened. Some 10,000 heart attacks a year could have been prevented in the UK if people had taken statins properly⁽⁷⁾.

Not all doctors are challenged by the idea of sharing power however, indeed some consider it a potential advantage. Dr Brian Fisher is a General Practitioner in Lewisham, South London. His practice was one of the first to invite patients to read their hand-written medical records while sitting in the waiting room. Unsurprisingly therefore, the practice has been among the forerunners of utilising

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technology to increase patient autonomy. Patients can now examine their electronic patient records, and view trusted web-based knowledge resources, within a confidential booth, while visiting the surgery. Dr Fisher says that there are multiple benefits including correcting recording errors and increasing the sense of a shared partnership between patient and professional⁽⁸⁾. There is also evidence that record access improves adherence to prescribed treatment⁽⁹⁾.

WHO TO TRUST?

The validity or otherwise of the material uncovered by the patient is perhaps the most problematic issue. Trying to determine which of the various sources of information are reliable is difficult enough for the trained clinician, even more so for patients. A glance at any newspaper on a given day will demonstrate that much of what is printed about health is potentially misleading, sensationalistic and liable to be biased. Even material that appears to come from patient groups may be tainted with pharmaceutical self-interest^(10,11). In its extreme form, this now includes the wonderfully named practice of “astro-turfing”, setting up fake grass-root patient groups in order to sidestep directly to consumer advertising bans⁽¹²⁾.

There are however reasons to be optimistic. There is now a vibrant marketplace of high-quality knowledge resources aimed at informing the public. Importantly, these products share an aim to reduce bias by being evidence-based, and to provide helpful information to assist informed decision making. In doing so, many explicitly highlight their intention to strengthen the partnership between clinician and patient, not to undermine it. Many also demonstrate a move away from a textbook “one size fits all” approach, to one that is aimed at mobilising the evidence around the particular circumstances of individual patients, and concentrating on key decision points. The importance of patient choice, preferences and values are central to evidence-based medicine (EBM)⁽¹³⁾. Without this recognition, EBM risks being viewed as simply promoting historic authoritarian practice where the expert knows best.

The Cochrane Collaboration now publishes plain language summaries of published systematic reviews aimed at informing the public, and the collaboration has been innovative in including the voice of consumers at all levels of its activities (www.cochrane.org). Building on the Cochrane Library, Informed Health Online (www.informedhealthonline.org) has recently been launched in English in May 2006. It had previously

been published in German since February 2006 by the German Institute for Quality and Efficiency in Health Care (IQWiG). IQWiG was established by legislation as part of Germany’s 2003 health reforms and is an independent, non-government and non-profit foundation that is intended to support evidence-based decision making in the German healthcare services. IQWiG undertakes and publishes assessments of the effectiveness, quality and efficiency of healthcare services. These cover areas ranging from diagnostic and therapeutic interventions, to disease management programmes and the assessment of clinical guidelines. Informed Health Online’s content relies heavily on the results of Cochrane systematic reviews. However, it also provides video and decision aid material aimed at assisting the public in making informed health decisions.

Similarly, the UK National Institute for Health and Clinical Excellence (NICE), and other major systematic reviewing and guidelines providers increasingly provide patient summaries of their guidance and health technology assessments⁽¹⁴⁻¹⁶⁾.

In the UK, the NHS Direct Online website⁽¹⁷⁾ (www.nhsdirect.nhs.uk) aims to provide unbiased advice for patients and Connect for Health (formally the National Programme for Information Technology) has made supporting the information needs of patients a high priority⁽¹⁸⁾. Other websites aimed at providing content for patients include Patient UK (www.patient.co.uk) and WebMD (www.webmd.com).

While these initiatives are to be welcomed, they also demonstrate some of the challenges in translating complex evidence for the public⁽¹⁷⁾. On the one hand, it is easy for people who are experienced in a given field to assume more technical knowledge than is to be expected in an unfamiliar audience. Conversely, oversimplification can lead to material being uninformative or misleading. Clinicians, however well motivated, understandably struggle to achieve the right balance between these extremes, and in general, the most useful material makes use of individuals with specific skills in translating complex scientific material for the public.

PRESCRIBING KNOWLEDGE

BestTreatments, a website created by the British Medical Journal (BMJ), (see conflict of interest below) aims to ensure that patients have access to the same evidence-based information their doctors are (hopefully) reading.

Launched first in the US in 2001, and subsequently in the UK and elsewhere, BestTreatments now publishes evidence-based, in-depth information on

well over 100 conditions, including major chronic disorders such as cancer, back pain, depression and arthritis. Based on *Clinical Evidence*, also from the BMJ Publishing Group and recognised internationally as the gold standard for evidence-based information for doctors, BestTreatments fully describes, in plain, jargon-free language, the benefits and risks of thousands of different treatments, based on the best research; and it also includes material to help people understand their condition, what it may mean for their lives and how they can help themselves. The site also includes information on the benefits and risks of some 20 common operations and tests including hip replacement, hysterectomy, and colonoscopy.

Crucially, BestTreatments uses specialist writers, editors and clinician advisers to ensure that the material is both credible and comprehensible to its chosen audience. In recognition of this, BestTreatments has been awarded the Plain English Campaign's Internet Crystal Mark and was independently judged as one of the most readable of 15 patient websites in the UK by research from Bath University⁽¹⁹⁾. Because it is based on *Clinical Evidence*, it also improves communication between doctors, nurses, and patients. BestTreatments is aimed specifically to be understood by people with a reading age of nine years – the average reading age in the UK.

Like *Clinical Evidence*, all topics contained within BestTreatments are annually updated to take account of new research. The aim is to help people choose, in partnership with their doctor, the treatments that are right for them. On the evidence so far, doctors in the UK find this site a help rather than a hindrance in consultations. Since BestTreatments is published by the BMJ and is based on *Clinical Evidence*, clinicians can trust the site and confidently recommend it to patients.

An example of how BestTreatments helps people gain a balanced picture about treatment was its explanation of research on the breast cancer drug herceptin in women with early breast cancer. While press reports focussed on the relative risk reduction of herceptin, with headlines such as “Drug halves breast cancer returns” (BBC), BestTreatments explained the research behind the headlines. The study being quoted in the press found that after three years, 87% of women who had the drug were cancer-free; among the group who did not get herceptin, 75% were also cancer-free. BestTreatments reported that in the same study, nearly one in five women had to stop taking herceptin because it was linked to heart problems, an important factor that other media had not reported⁽²⁰⁾.

Founded by Don Kemper in 1975, Healthwise® is one of the major providers of patient content. Healthwise® aims to assist patients in providing informed decisions. Kemper is credited with coining the term “information therapy” to reflect the new opportunities for clinicians to prescribe knowledge rather than simply issuing a prescription⁽²¹⁾. Like other providers, Healthwise® makes much of their mission to encourage patients to become more informed and to take an active part in their care, building their material around decision points. They also point to the health and cost benefits that occur when patients and clinicians make better health decisions⁽²²⁾.

“If information doesn't help people make better decisions, it doesn't help – plain and simple”.

DECISION AIDS

The Ottawa Health Research Institute (OHRI), led by Professor Annette O'Connor, is an international team that designs and tests decision aids and training programmes for patients and health practitioners. The mission of the OHRI is “to explore better ways to help patients make ‘tough’ healthcare decisions that may have:

- multiple options;
- uncertain outcomes;
- benefits and harms that people value differently.”

The Ottawa Personal Decision guide (<http://decisionaid.ohri.ca/decguide.html>) is a generic tool that supports people in making decisions, by inviting the user to reflect on issues such as the level of knowledge (whether he/she knows enough to make the decision), values (whether he/she understands enough about what matters to him/her) and level of support (what is needed from others in order to make the decision). The tool is available online in interactive formats and also to print and fill out in writing.

The Ottawa unit have also developed their own decision aid tools (<http://decisionaid.ohri.ca/decaids.html>) that build on the generic platform to provide specific decision aids tailored to individual decisions. Examples include whether to take non-steroidal anti-inflammatory drugs (NSAIDs) for osteoarthritis, and the different surgical options for women with breast cancer. These aids are available in interactive internet applications, and also in audio and printed formats.

Building on this, OHRI has assembled an inventory of available decision aids (<http://decisionaid.ohri.ca/AZinvent.php>). The inventory includes aids developed by the Foundation for Informed Medical Decision Making

(FIMDM) (<http://www.fimdm.org>) whose mission is to strengthen the role patients play in selecting treatments for their medical conditions. To achieve this, the foundation provides a theoretical framework that aims to improve the quality of decisions patients make in collaboration with their physicians. This ensures that patients understand the perspectives and information they need when they face decisions about medical testing and treatment. The foundation's work is founded on two premises: that patients need to understand why it is in their interest to participate fully in decision making, rather than delegating decisions to their doctors; and also that they need to understand their options thoroughly. Like BestTreatments, FIMDM programmes present the latest evidence about risks and benefits of treatment options in ways that patients can understand, and explain where evidence is lacking or inadequate. In addition, the programmes include interviews with patients who have undergone treatments and experienced good and bad outcomes.

DO DECISION AIDS WORK?

In a systematic review performed by OHRI, over 200 decision aids were identified, 131 of which were intended for use before counselling by a professional. 30 aids had been evaluated in 34 randomised controlled trials (RCTs), and the review also identified a similar number of studies where evaluation was ongoing. Compared with usual care, decision aids scored better for outcomes such as knowledge, realistic expectations, active role in decision making and the likelihood of making a decision. The reviewers comment that outcomes such as adherence to chosen path, cost effectiveness and methods of dissemination require further studies⁽²³⁾.

CONCLUSION

Patient empowerment is here to stay. The internet is one factor certainly, but there are other societal influences that have led to this situation. In all areas of health, from policy and service planning to the individual consultation, the patient voice is being heard and orthodoxy based on the rule of the expert is being challenged. While predicting future trends is never easy, it is likely that these changes will continue and perhaps even accelerate, as innovative new media delivery mechanisms, including 3G mobile phones and DVDs, mean that video can be easily incorporated. Increasingly it will be possible to personalise the messages to the needs and preferences of individual patients. In time, this will include filtering content through the electronic patient record to customise the information even further.

What we may envisage is that gradually evidence-based and patient-centred medicine will come closer together. This may be difficult for doctors, but it is also leading to some innovative solutions and insights.

Iain Chalmers has been in the forefront both of the Cochrane Collaboration and also, latterly, in increasing the voice of patients within clinical research. He founded the James Lind Alliance (JLA) (<http://www.lindalliance.org>) which is working to increase the priority and awareness of research into issues of importance to patients and clinicians. The JLA is also constructing the Database of Uncertainties about the Effects of Treatments (DUETs) (<http://www.duets.nhs.uk>), which aims to identify important clinical questions for which there is as yet no definitive answer. In a landmark book, Chalmers, along with co-authors Imogen Evans and Hazel Thornton, urges that clinicians and patients work together to ensure that evidence on effects and uncertainties is widely disseminated, that research aimed at addressing important areas of uncertainty is conducted, and that patients are encouraged to participate in research aimed at addressing areas of ignorance⁽¹⁰⁾.

These moves aim to channel patients' natural interest in understanding more about health. Building on this, researchers have used the internet to conduct clinical research, enabling much wider participation.

How should the clinician guide the patient to trusted studies and services? For individual studies, particularly those reported in the media, there are a number of key issues.

- For reports of new treatments, it should nearly always be possible to undertake RCTs where the novel therapy is compared with existing treatments in otherwise similar groups of people.
- There may need to be some consideration of study quality measures, tendencies towards bias (including publication bias), and explicit reference to previous similarly-constructed studies or systematic reviews. For further description of standards for reporting RCTs and systematic reviews, see the Consort and Quorum statements, respectively (<http://www.consort-statement.org>).
- When reporting relative differences, researchers should do so only in association with either absolute effects or baseline risks. Reports that only cover relative effects will tend to exaggerate the benefit to patients, particularly where the risk of a given outcome is low. The media coverage of the herceptin issue is a good example of this⁽²⁰⁾.
- Where benefits are reported, there should also be a reference to harmful effects, or a statement that these were not studied.

For evaluating services and products, clinicians may prefer to recommend products and services which are rigorous, independent and systematic. The checklist therefore should include an enquiry into the transparency with respect to funding and methods, and also the rigour of the processes that underpin any recommendations. Unfortunately, the increasingly ubiquitous term “evidence-based” is no guarantee of the latter, unless it is restricted to those resources that use systematic approaches to identifying evidence and critical appraisal of the literature using methods aimed at reducing the effects of bias. Additionally, many health resources are reliant on pharmaceutical advertising. While it remains theoretically possible to ensure editorial independence in this context, the reader must judge the likelihood of subtle or unacknowledged influence.

What binds all this together is the hypothesis that the benefits of bringing the best possible information to the patient, promotes partnership between doctors and the public. The task of ensuring the knowledge is free from bias, dispassionate, systematically-derived, relevant, current and accessible is considerable. However, the potential benefits to patients and their doctors are also substantial. In his MacKenzie lecture, Fugelli⁽⁴⁾ suggested that partnership and trust building would lead to a reduction in the collective “angst” (complaints, litigation and the fear of these) that has been so prominently discussed over recent years⁽²⁴⁾.

Perhaps it is time not to fear the patient bearing reams of paper, but to appreciate the industry and sense of responsibility that the action implies. In the future, doctors may prescribe the use of trusted resources, and encourage patients to learn to critically evaluate sources more rigorously, with the aim of making more informed clinical decisions in partnership.

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SINGAPORE MEDICAL COUNCIL CATEGORY 3B CME PROGRAMME

Multiple Choice Questions (Code SMJ 200609A)

	True	False
Question 1: Some possible reasons why doctors may experience “heartsink” or alarm when a patient presents with information and computer printouts from the internet are:		
(a) Usurping of the doctor’s historical role as provider of information.	<input type="checkbox"/>	<input type="checkbox"/>
(b) Improving partnership working between clinicians and patients can lead to improved healthcare outcomes.	<input type="checkbox"/>	<input type="checkbox"/>
(c) Doctors may be chary of shared decision making and feel that “doctor-strength” information will only confuse patients.	<input type="checkbox"/>	<input type="checkbox"/>
(d) Perceiving that the authority of the doctor is undermined.	<input type="checkbox"/>	<input type="checkbox"/>
Question 2: Factors thought to increase trust in doctors include:		
(a) Sharing power with patients.	<input type="checkbox"/>	<input type="checkbox"/>
(b) Competence.	<input type="checkbox"/>	<input type="checkbox"/>
(c) Moral integrity.	<input type="checkbox"/>	<input type="checkbox"/>
(d) Determining what patients should or should not know.	<input type="checkbox"/>	<input type="checkbox"/>
Question 3: Indicate whether the following statements are true or false:		
(a) Patient education materials that come from patient groups are always unbiased and reliable.	<input type="checkbox"/>	<input type="checkbox"/>
(b) Patient choice, preferences and values are central to evidence-based medicine.	<input type="checkbox"/>	<input type="checkbox"/>
(c) Summaries of systematic reviews published by the Cochrane Collaboration are aimed only at doctors and other healthcare professionals.	<input type="checkbox"/>	<input type="checkbox"/>
(d) “Information therapy” is a term coined to reflect the new opportunities for clinicians to prescribe knowledge rather than simply issuing a prescription.	<input type="checkbox"/>	<input type="checkbox"/>
Question 4: Indicate whether the following statements about decision aids are true or false:		
(a) Decision aids are tools to help people make decisions.	<input type="checkbox"/>	<input type="checkbox"/>
(b) Use of a decision aid will always assist the patient to make the right decision.	<input type="checkbox"/>	<input type="checkbox"/>
(c) Some decision aids can be found on the internet.	<input type="checkbox"/>	<input type="checkbox"/>
(d) Studies show that compared with usual care, decision aids scored better for outcomes such as knowledge, realistic expectations, active role in decision making and the likelihood of making a decision.	<input type="checkbox"/>	<input type="checkbox"/>
Question 5: Key issues to consider when guiding patients to trusted studies and services include:		
(a) Patients should be advised to look only for well-conducted cohort or case-control studies for reliable information on new treatments.	<input type="checkbox"/>	<input type="checkbox"/>
(b) Patients do not need to consider bias in studies, since any published study has undergone peer-review and is therefore reliable.	<input type="checkbox"/>	<input type="checkbox"/>
(c) When reporting relative differences, researchers should do so only in association with either absolute effects or baseline risk.	<input type="checkbox"/>	<input type="checkbox"/>
(d) Where benefits are reported, there should also be a reference to harmful effects, or a statement that these were not studied.	<input type="checkbox"/>	<input type="checkbox"/>

Doctor’s particulars:

Name in full: _____

MCR number: _____ Specialty: _____

Email address: _____

Submission instructions:**A. Using this answer form**

1. Photocopy this answer form.
2. Indicate your responses by marking the “True” or “False” box
3. Fill in your professional particulars.
4. Post the answer form to the SMJ at 2 College Road, Singapore 169850.

B. Electronic submission

1. Log on at the SMJ website: URL <<http://www.sma.org.sg/cme/smj>> and select the appropriate set of questions.
2. Select your answers and provide your name, email address and MCR number. Click on “Submit answers” to submit.

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1. Answers will be published in the SMJ November 2006 issue.
2. The MCR numbers of successful candidates will be posted online at <http://www.sma.org.sg/cme/smj> by 15 November 2006.
3. All online submissions will receive an automatic email acknowledgment.
4. Passing mark is 60%. No mark will be deducted for incorrect answers.
5. The SMJ editorial office will submit the list of successful candidates to the Singapore Medical Council.