World Library and Information Congress:
70th IFLA General Conference and Council

22-27 August 2004
Buenos Aires, Argentina

Empowering patients through health information literacy training

Rowena Cullen
Associate Professor
School of information Management
Victoria University of Wellington
Wellington, New Zealand

Abstract

> *There is a vast amount of consumer health information available to users on the World Wide Web, but it is of very varying quality. At the same time, healthcare providers are now espousing the principles of shared decision-making and informed consent in the delivery of health services, but these principles depend on access to high quality information, and information about treatment options, in a way that health consumers can understand. How can health information professionals, in the brief contact they have with health consumers, help them locate and evaluate appropriate information in the most effective way. The paper explores some aspects of health information literacy training that are fundamental to enable health consumers find, evaluate, and use, print and online information sources, and some of the critical factors in effective health information literacy programmes. These are: the principles of effective teaching, critical thinking, and the use of health information quality instruments, such as DISCERN.*

Introduction

Health information professionals are faced with some new tasks in the emerging environment of the 21st century. The revolution in information and communication technologies (ICTs), and their impact on the dissemination of information, has resulted in a vast amount of professional and consumer health information becoming available on the World Wide Web. At the same time,

there has been a change in the relationship between healthcare providers, and patients, or health consumers, that is driven by a number of factors. These include:

- an increasing awareness of citizen, patient and consumer rights;
- the demystification of the medical sciences;
- the development of the principles of evidence-based healthcare;
- an increasing requirement for accountability throughout public and private services;
- a new democratised and informed public.

These influences are affecting healthcare service provision around the world, whether in developed or developing countries, and leading to an emphasis on informed consent in medical decision-making. They are also placing demands on health information professionals, who are responding by developing consumer health information services, either face to face, or on the web, and who are taking on board their role as intermediaries and educators, assisting health consumers to find the information they need, and teaching them to become 'self-activated, self-responsible' health consumers.[1] In this new role, health information professionals must develop an understanding of several key elements of effective health information literacy education: the need for consumer health information, the principle of informed consent, information literacy and critical thinking, the principles of effective teaching, and the criteria for evaluating consumer health information resources. The paper discusses each of these in turn, and highlights briefly in conclusion some key resources that meet the significant evaluative criteria.

The need for consumer health information
There is an extensive literature about consumer health information, patients' needs for health and wellness information, and the adequacy or inadequacy of much of the information that has been available to them over the years.

This literature is based on two principles—the first is that because of their concern over health issues, for themselves, or their families or loved ones, people need to know how to maintain their health, how to treat minor illnesses and ailments, and to understand the nature of an ongoing or life-threatening condition, the treatment options available to them, and how to live with the condition. The second principle is that of informed consent. To participate in decisions concerning their own or their family's health care, and take personal responsibility for their own health people need information about the issues relevant to this, and to understand the risks and relative benefits of any treatment offered. Such information has not always been available, and health professionals have not always been willing to share it. This attitude was already changing. However, the Internet, with its vast resources of information available to health consumers, whether they are accurate and up-to-date or not, and whether they are intended for health consumers or professionals, has seen a revolutionary change in the amount and the quality of information available to health consumers to support their participation in decision-making

As Bob Gann, a longstanding advocate of consumer health, or patient information, comments in his 1986 *Health Information Handbook*, "information to enable participation in our health is important at all stages of our lives, but never more so than when we are faced with illness and

---

[1] Tom Ferguson, "The Health-activated, Health-responsible Consumer" in Alan Rees (ed.) *Managing Consumer Health Information Services* (Phoenix, Az: Oryx, 1991)

become patients. . . before we are able to cope with ill health, and communicate with professional carers, we need a basic understanding of our bodies, how they work, and the terminology used to describe them. Many people lack this knowledge."[2] Gann summarises, and cites research from the 1950s through to the 1980s that shows that patients, and their care-givers, lack information about the identification, placement and function of various organs, do not understand medical terminology for common conditions and diseases, do not feel that they have had a disease and its prognosis explained to them, and in a hospital or clinic setting do not know who provided treatment. He cites a now famous article by Clair Rayner, an 'agony aunt' for a popular British womens' magazine in the seventies, who lists the most common queries she deals with, (everything from anxiety over body changes at puberty, to reproductive health and childbirth, sexual and metal health problems), which she suggests highlight the failures of the National Health Service to respond to the concerns of patients, and the demand for health and wellness information.[3]

In addition to their general lack of knowledge about how their bodies work, most people, when confronted with the diagnosis of a major illness have difficulty retaining the information that may be given to them by their physician. Added to the problem of recalling new and unfamiliar verbal information about a newly diagnosed medical condition are added the factors of pain, stress, anxiety and sometimes fear, and what Faulder describes as a 'class distinction', factors now more commonly identified as socio-economic, ethnic and cultural barriers. Patients are put "at a distinct disadvantage when it comes to voicing their preferences or doubts to someone who speaks with a different accent, almost in a different language, and who is surrounded by the trappings of authority." [4] There is ongoing evidence reported in journals such as BMJ and JAMA, as well as the medial librarians' literature, of health consumers seeking information on the web and elsewhere, on routine health issues, medical terminology, and treatment options, indicating that the situation has not significantly changed in the further two decades since the extensive research outlined by Gann.[5] Recent research into Internet use by the Pew Internet & American Life project shows at least 80% of all adult Internet users in the US seek health information on the Internet, covering a very similar range of concerns, and often because they have not obtained this information from their own physician.[6]

However, in providing services and training for health consumers, to help them better meet these needs, it is also important to recognize that not all health consumers and patients respond to health and disability issues in the same way. Research shows that while some people respond to a serious health concern by avoiding new and threatening information, and prefer to trust the physician, and accept any decision s/he makes on their behalf, others deal with the situation by finding out as much as they can about their condition, including the best and worst prognosis, and

---

[2] Robert Gann "The informed patient" pp18-47 in The Health Information Handbook (Aldershott, Gower, 1986)

[3] Claire Rayner, ""Reality and expectation of the British National Health Service Consumer" Journal of Advanced Nursing 4 (1979): 69-77.

[4] Carolyn Faulder. *Whose body is it? the troubled issue of informed consent.* London: Virago, 1985.

[5] Robert Gann, "The Informed Patient" pp18-47 in *The Health Information Handbook* (Aldershot: Gower, 1986)

[6] Susannah Fox and Deborah Fellows. Internet Health Resources. Pew Internet & American Life Project. [http://www.pewinternet.org/reports/toc.asp?Report=95. Accessed 21/04/04]

treatment options, as a coping mechanism.[7] These two groups are often referred to as 'monitors' and 'blunters', 'monitors' seeking to find as much information as possible about their disease, and take responsibility for it, and 'blunters' avoiding such knowledge in order to block out new and threatening knowledge. 'Monitors' and 'blunters' may be found amongst patients, and also among their nearest support, partner, or care-giver. Ferguson divides patients into 'passive patients, concerned consumers, and health-active responsible consumers'. The latter he suggests, may seem aggressive in seeking out information about disease, alternative treatments, challenging their physicians and anyone else concerned with their care, and asserting control of the management of their illness.[8] We must recognize, however, that it may be the partner or care-giver who is the information seeker, and the 'health-active consumer' on the part of their 'patient'. As health information professionals, we need to build on all this knowledge and integrate it into our teaching of print and web-based resources to patients, and their families wherever we encounter them.

The principle of informed consent
Apart from emergency situations, where it may not be possible to obtain consent before urgent life-saving procedures are carried out, in most developed countries, the patient has some choice in whether or not to accept treatment, and what treatment to accept. If the prospective patient, or health services consumer can have, or can access, authoritative information and evidence about the efficacy of different treatments and surgical interventions, they are in a much better position to discuss with their healthcare professional the various options, and in the end to make up their own mind and exert patient choice.

This right is clearly articulated by the United Nations and the WHO (most recently in relation to genetic research), which acknowledges that:

> Patients' rights vary in different countries and in different jurisdictions, often depending on prevailing cultural and social norms. Different models of the patient-physician relationship—which can also represent the citizen-state relationship—have been developed, and these have informed the particular rights to which patients are entitled. In North America and Europe, for instance, there are at least four models which depict this relationship: the paternalistic model, the informative model, the interpretive model, and the deliberative model. Each of these suggests different professional obligations of the physician toward the patient. For instance, in the paternalistic model, the best interests of the patient as judged by the clinical expert are valued above the provision of comprehensive medical information and decision-making power to the patient. The informative model, by contrast, sees the patient as a consumer who is in the best position to judge what is in her own interest, and thus views the doctor as chiefly a provider of information. There continues to be an enormous debate about how best to conceive this relationship, but there is also a growing international consensus that all patients have a

---

[7] Tom Wilson and Christina Walsh, *Information Behaviour: An Inter-Disciplinary Perspective* . British Library Research and Innovation Report 10. Chapter 2. Information Seeking Behaviour.[http://www.shef.ac.uk/is/publications/infbehav/chap2.html. Accessed 21/04/04]

[8] Tom Ferguson, "The Health-Activated, Health-Responsible Consumer, pp15-22 in Alan Rees, ed. *Managing Consumer Health Information Service*s (Phoenix Az:Oryx, 1991

fundamental right to privacy, to the confidentiality of their medical information, to consent or to refuse treatment, and to be informed about the relative risk of medical procedures. [9]

These rights are legislated in many countries, as in the original United Kingdom Patients' Charter, now absorbed into *Your Guide to the National Health System*, which clearly articulates the patient's right to "have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide to agree to it."[10] In Australia, patients rights are dealt with at State level- the primary level for delivery of care. The Victorian Government's Health Information Service, therefore, promotes the Public Hospital Patient Charter, including, the right to participate in making decisions about treatment and care. "You should be fully involved in decisions about your care and be given the opportunity to ask questions and discuss treatments so you understand what is happening."[11] In the United States, such rights are voluntarily covered by the American Hospital Association's Patient's Bill of Rights, which includes the statement that "the patient has the right and is encouraged to obtain form physicians and other direct caregivers relevant, current, and understandable information concerning diagnosis, treatment and prognosis . . . to discuss and request information related to specific procedures and/or treatments, the risks involved, the possible length of recuperation, and the medically reasonable alternatives and their accompanying risks and benefits, . . . [and] to make decisions about the plan of care prior to and during the course of treatment." [12]

However, none of these statements (which, except for the NHS Guide, refer only to hospital-based treatment and not private outpatient or primary care) provide guidelines as to how much information patients need in order to participate in decisions concerning their care—decisions which often present considerable dilemmas and difficult choices for clinicians themselves—nor how and when it should be presented. And although, in the past, in theory, it has always been possible for a patient to have choice, in practice, patients had little alternative but to accept a doctor's choice and recommendation, and even the practice of 'getting a second opinion' was not always supported by all medical practitioners. Until recent times, the medical profession set the standard for the information which should be given at the time consent is obtained. With the advent of the Internet, and the extensive files of both consumer and professional health information on the World Wide Web readily accessible to patients, that control of both the amount, and content of information available to patients has shifted to the patient rather than the physician. Helping them access it is a legitimate role for health information professionals.

Information literacy
Increasingly, information professionals are expected not just to help people find information, but to help them master the complexities of the information age and acquire lifelong information

---

[9] World Health Organisation. Genomic Resource Centre. *Patients' rights.*
http://www.who.int/genomics/public/patientirght/en [accessed 11/03/04]

[10] Check wording and current source of this with Bruce Madge

[11] State Government of Victoria. Department of Human Services. Victorian Government Health Information. Public Hospital Patient Charter. http://www.health.vic.gov.au/patientcharter/patients.htm [accessed 11/03/04]

[12] American Hospital Association. AHA Management Advisory. A Patient's Bill of Rights. 1992. [Accessed 11/0/3/04]

problem-solving skills, the set of skills which are now usually referred to as 'information literacy'. As we have seen, given the need for health consumers to be able to find, retrieve, evaluate and apply the information they need to care for themselves and their families, and to give informed consent to medical procedures, this mission to give people life-long information literacy skills, especially in the health area, becomes critically important.

Information literacy is generally defined as something much broader than just library/information retrieval skills. Information literacy training should start, as literacy does, with the earliest stages of education, and the encouragement of critical thinking in the very young. Ideally information literacy should be a key part of all educational processes, from primary school through to graduate study at the tertiary level. It is a key skill which is essential for every citizen's participation in democracy and the knowledge economy, as well as participation in decisions about each citizen's health care. Information literacy is therefore not just a library issue, but a broadly based education and learning issue, and a health issue. However, the information professions can play a critical role in promoting it, and in teaching their users the skills that go to make up an information literate person.

Critical thinking
One of the major components of life-long learning and information problem-solving that is generally discussed in conjunction with information literacy is critical thinking. This is a harder concept to define and to teach. Critical thinking involves curiosity, scepticism, reflection, and rationality. It has been defined as the formulation and use of criteria to make warranted judgements about knowledge claims. At a simple level it may be enough to teach children to ask a range of "Who, What, Where, Why, When and How" questions about a problem, and to evaluate the resources they find by a simple set of criteria such as those used by reference librarians, trained to assess the authority, accuracy, currency, scope and purpose of the sources they use. At a more complex level it involves challenging assumptions, and looking for the underlying characteristics of the reasoning involved in a statement, using the principles of informal logic to detect incorrect, false or misleading reasoning in statements, or propositions.

Librarians rarely find themselves teaching critical thinking at this level unless they have some experience of the formal study of philosophy, but we can all try and develop in our own thinking, and when teaching information literacy skills to others, some simple techniques that focus on analytical questions, as well evaluative questions, in order to detect incorrect reasoning.

Evaluative questions ask . . . Is this information relevant? Is this information likely to be accurate? How can I tell if this is current?. What is the source of this information? Is it reliable? For each of these questions, criteria can be developed that will help people answer them with confidence.

Analytical questions ask . . . What are the assumptions being made here? What evidence is offered here for this statement? How well does this evidence stand up to scrutiny. Are all sides of the question fully covered or is there an element of bias here? Tools such a critical appraisal can be used to help develop criteria here, or users can be pointed at resources which have been evaluated by others with appropriate skills to do so.

Techniques of effective teaching, and learning

Good teaching is based on good planning, and on determining the purpose of the instruction beforehand. Although every encounter between a librarian and a user, or health information professional and a health consumer may provide a 'teachable moment', thinking about good teaching means that we should approach even such informal encounters with well-honed teaching techniques, and within a well-developed teaching framework. There are a number of key steps which must be addressed.

1. Determine the purpose of the instruction, your goals, which must then be translated into simple, active, learning objectives for your clients (or readers, or the health consumer).

2. Identify what your audience already knows—start at their level, not above or below it, (avoiding assumptions about what terms they know, or don't know, and making sure all complex terminology, whether it is library, web or medical terminology, is clearly and simply defined).

3. Incorporate critical thinking into your instruction. Teach people to scrutinize and challenge any information or source they come across, with simple techniques such as using 'who, why, what, where, and how', but also by providing them with criteria that they can take away and apply to information sources.

4. Decide how you will present the material (oral only, oral and written, electronic display etc., and if you need it in a range of languages) in a way that suits the needs of the audience—not your needs—and prepare well in advance, so that there is time for checking, and testing the material. This can apply to that magical one-to-one teachable moment as much as a formal class, if you have anticipated the moment, and have well-prepared material to hand.

5. Feedback and follow-up. It is critical that any instruction you give is evaluated by the people for whom it is intended to help. Focus on the learning objectives that you set and whether they are fulfilled—not whether people enjoyed the instruction, or the experience, or feel more confident, but whether they can now perform a task that they couldn't before.

Finding and Evaluating Consumer Health Information, and how to teach this

While many of the principles outlined below focus on resources on the World Wide Web, it is important not to neglect print resources, and even audio-visual resources (which have been very effectively used by the Consumer Health Information Services at Beth Israel Hospital in Boston, as reported at the meeting of the Health and Biosciences Libraries section at IFLA in 2001). The main criteria here are the same as for any information source offered to patrons by information professionals—that they should be accurate and up-to-date, from a trusted authoritative source, unbiased, clear in defining their purpose, scope, and audience, and at a suitable level for the intended use. These criteria become critically important in the field of consumer health information. The level of language used, and the need for clear definitions of any medical or technical terms are especially important, and it is quite common to see health information resources evaluated using 'readability' indexes such as the Fog[13] or Flesh indexes.[14] But equally

---

[13] http://www.as.wvu.edu/~tmiles/fog.html [Accessed 21/04/04]

important is the trusted authority of the source, and the accuracy and currency of the content. There is a great deal of evidence that the majority of consumer health information sources on the Web do not meet these basic criteria,[15] including a recent URAC report which investigated both the quality of resources, and the ability of health consumers to identify quality information.[16] (There is also a great deal of printed information available that also does not meet them either— but librarians have been dealing with that issue for a long time, and have hopefully relied on their own professionalism to carefully select on this basis the resources that they supply to health consumers.)

Standards for web-based Consumer Health Information
In the context of the World Wide Web, because health consumers are searching for information for themselves, and making their own choices about information sources, rather than relying on quality-filtered information supplied by a health practitioner or information professional, our professional responsibility is to teach and promote the principles of retrieving and evaluating consumer health information on the Internet. There are some excellent guidelines available for this purpose—the well-known Health on the Net Foundation (HON) Hon Code 'badge' assures users that certain principles have been followed. These include: Authority (especially that any medical advice provide will only be given by a medically trained professional unless otherwise stated); complementarity (a clear statement that any information provided does not replace the relationship between a patient and their doctor); confidentiality, attribution (date, and source, of information, and if possible a direct link to source data); justifiability (documentary evidence of any claims made); transparency of authorship (and contact details); transparency of sponsorship; honesty in advertising and editorial policy. Detailed guidelines in support of each of these are linked to each principle.

The URAC Health Web Site Standards[17] cover a slightly different set of principles, and suggest that overt statements should cover: *Disclosure*: what services are provided, and the terms and conditions of these; response times for email and other communications; what information is collected about users, and how any personally indentifiable information is handled; ownership of the site, significant investors, editorial and advertising policy etc. Under *Health Content and Service Delivery* accredited web sites are required to have: an editorial policy with clear statements about minimum qualifications of authors of health content, and policies for review of health content, claims of any therapeutic benefit must have 'reasonable' support, and false or misleading claims are not knowingly promoted; the name of the author and date of material is supplied; any conflict of interest disclosed.
The DISCERN instrument was developed by health information professionals to provide criteria for evaluating print materials, but has been found very useful for evaluating consumer health web

---

[14] http://www.mang.canterbury.ac.nz/courseinfo/AcademicWriting/Flesch.htm [Accessed 21/04/04]
[15] Q R Huang. Creating informed consumers and achieving shared decision making. *Australian Family Physician*. 2003 May;32(5):335-41.
[16] Liza Greenburg, Guy D'Andrea, and Dan Lorence. Setting the Public Agenda for online Health Search. A White paper and Action Agenda. Washington: URAC, 2004 [http://www.urac.org. Accessed 21.03.04]
[17] Health Web Site Standards. Version 1.0. Washington D C: URAC, 2001 [http://webapps.urac.org/websiteaccreditation/default.htm. Accessed 15/04/04] URAC is an independent accreditation body for US health services, and hospitals.

sites as well. [18] It is therefore recognisably closer to the 'reference librarian's' mindset. DISCERN's criteria ask: Are the aims of the site clear? Does it achieve its aims? Is it relevant? Is it clear what sources of information were used to compile the publication (other than the author or producer)? Is it clear when the information used or reported in the publication was produced? Is it balanced and unbiased? Does it provide details of additional support and information? Does it refer to areas of uncertainty? How good is the quality of information on treatment choices? Does it describe how each treatment works? Does it describe the benefits of each treatment? Does it describe the risks of each treatment? Does it describe what would happen if no treatment is used? Does it describe how the treatment choices affect quality of life? Is it clear that there may be more than one possible treatment choice? Does it provide support for shared decision-making?

Each of these has a slightly different approach to the problem, and a different view of what will 'empower' health consumers to give informed consent, and participate in a shared decision about treatment. It is a difficult task to pick out from each some key principles to communicate to health consumers seeking information. Since the HON badge is likely already to be on any consumer health site of value, (if it is not, we should immediately suggest application be made) perhaps we can agree that these criteria have been tested already if the HON badge is present, and only need to integrate the concerns about commercial integrity and independence of editorial policy from URAC (which are also emphasised by the HiEthics Working party,[19] and the Health Summit Working Group sponsored by Mitretek and HITI[20] with those of DISCERN. We emerge with a set of new criteria which fall under two distinct headings: commercial integrity, and complete health information

Thus, by pulling together the principles of teaching and critical thinking, we can focus on some key principles which will be able to be conveyed to consumers or library users in a classroom situation, a face to face interchange, or on a web site, where health consumers are given advice, and some instruction in searching and evaluating informaiton. A range of learning objectives that could be set for this purpose would include things such as:

At the end of this class participants will be able to:

• search the World Wide Web for health information using appropriate keyword to retrieve health information;
• apply a set of quality criteria to resources identified, based on known quality instruments;
• identify portals and specific web sites providing high quality health information from trusted sources;
• find whether sufficient information is provided in a resource about authorship, and evaluate the clinical or professional credentials of author, and that these are appropriate for the level of advice being given;
• confirm that all material is sourced (and if possible linked to source (e.g. in PubMed);
• check date of material, and that dates on source material are recent, or if not recent, there is an acceptable reason for using older material;

---

[18] http://www.discern.org.uk [Accessed 15/04/04]
[19] http://www.hiethics.com/ [Accessed 21/04/04]
[20] http://hitiweb.mitretek.org/info/projects.asp [Accessed 21/04/04]

- show that the information provided contains appropriate explanations and language levels for non-medical readers;
- demonstrate that risks as well as benefits of any treatment are discussed;
- demonstrate that more than one alternative treatment is discussed, including the potential risk of no treatment;
- identify if there is a potential for conflict of interest between commercial concerns and the health information content;
- ensure that all appropriate steps are taken to secure the privacy and confidentiality of the user.

While it would not be possible to cove all of these in a short session, and some depend in prior understanding of key concepts that might also have to be taught, they are indicative of the kinds of learning objectives that are appropriate to consumer health information education. However, in a simpler context, maybe you can fall back on the truest friends any information professional ever had, the six honest serving men, 'Who, What, Where, When, Why, and How': Who wrote this, why did they write it, and why do they want me to read it? What are they trying to do in this web site? Where did they get their information from? When was it written, when was the research carried out? How can I tell if this is unbiased and honest information?

Evaluating some of the best consumer health web sites
Finally, we can now look at some of the best and most well-regarded consumer health information web sites and see how they stack up with our set of criteria (which include the standard reference ones of authority, purpose, scope, accuracy, currency and level) and our new health information professional ones of commercial integrity, and complete health information. Below we take a quick look at NOAH, Medline Plus, InteliHealth, and the site of the National Cancer Institute

NOAH (New York Online Access to Health)
NOAH is a consumer health information portal which was originally developed by New York Public library, the New York Academy of Medicine, and other New York city libraries. It contains carefully filtered links to other web sites on a vast range of topics, and tries to find information in Spanish, and other European languages. On the basic criteria of authority, purpose and scope, NOAH rates very highly, being very open about its mission and policies. It covers a very extensive range of subjects in English and Spanish where possible. Team members are named, and most information is dated. However, most of the information provided comes from external sources, already evaluated for quality, according to NOAH's stated principles. It is to these links we must turn to evaluate the resource further.

Links to relevant information are organised under broad headings (typically Basic facts, Medications and treatments, Issues and concerns, and Clinical trials). For example, a query on Lupus links to several major institutes carrying out research and promoting information about the disease including the Lupus Foundation—all information provided here is clear, the authors and their credentials well identified, treatment options are discussed in some detail. A weakness is that material is not properly sourced, and some of the articles on the Foundation's web site, written by staff, and approved by their Patient Education Committee are not very recent. But in other respects the information meets the criteria well. Noah has received a number of awards for excellence, e.g. from the MLA, and CAPHIS, but does not carry the HON badge.

Medline plus
Medline plus is the Consumer part of the National library of Medicine's public access Medline database, PubMed. It carries the authority of the National Library of Medicine and the National Institutes of Health.   Its purpose, and editorial policies are clearly stated on the About MedlinePlus pages, it maintains a high level of accuracy and is updated daily.   The level and language of the information provided are clearly indicated in headings used. Medline Plus is a mixture of original information sources and links to other information.

Using the same search, on Lupus, an initial simple explanation is given and a list of subdivisions of the topic, which are similar to NOAH's (covering basic information, clinical trials, coping, diagnosis, symptoms and diagnosis and disease management).
Initial links are only to other parts of the National Institutes of Health, of which National Library of Medicine is in particular the National Institute of Arthritis and Musculoskeletal and Skin Diseases, but other links are to similar institution as the NOAH sites links to (e.g. Mayo Clinic), and many link back to the National Lupus Foundation. Like many of the NIH Institutes, although staff leading research are named, and there are frequent links to other information sources, and clinical trials, the information does not fully meet all the requirements for a named author, date of information, and source references. Under treatment there are also a number of links (including one to the Lupus Foundation) but no clear-cut path through these to ascertain treatment options and the risks and benefits of each.

Intelihealth
The Intelihealth site is sponsored by Aetna, and uses the Harvard Medical School's Consumer health Information service. It relies on the authority of the Harvard Medical School staff contributing and overseeing its content,, but its purpose is less clear. Its ownership by Aetna, and the presence of advertisements and news items suggests a more commercial orientation, and its content is much simpler and less informative than Noah and MedlinePlus. Because of its commercial focus it carries statements about its commercial integrity and editorial distance from commercial interests-more so than the other 'public good' or research foundation sites looked at above where this is perceived to be less of an issue.   Its information on a topic such a Lupus is basic, although there are links to research institutes such as the National Institute of Arthritis and Musculoskeletal and Skin Diseases, and the Lupus Foundation. The information is not sourced, dated and carries no named author, although the policy statements indicate that all medical material is written by Aetna staffers or contracted staff from Harvard Medical School, and approved by faculty members. Searching on drugs listed as effective for this disease takes you to the American Pharmaceutical Society's Safemedication.com web site which provides information on side effects, and risks. It is hard to garner from this process, and other links the information that the informed consumer is entitled to. Other news articles available on the site covering hot topics, and recent research carried out at Harvard are signed and dated. The site carries the URAC and the HON code badges.

National Cancer Institute
(http://www.nci.nih.gov/cancerinfo/ can also be reached through www.Cancer.gov
The site carries the full authority of the Institute, and its purpose is part of the Institute's mission of disseminating information about cancer and research on cancer, one of many statements about the work of the Institute that is easily accessible on the web site. The scope is enormous, and

covers all types of cancer, and all known treatments. It is current- to the extent of discussing new and unproven treatment, and at the cutting edge of knowledge. Accuracy is exemplary, for a field where there is till much controversy.There is more original material on this site (not unexpectedly since it is the wealthiest Cancer research institute in the world), but that information is admirably presented to respond to consumer concerns. Headings on the initial page cover clinical trials, research and basic information, and lead quickly to information by type of cancer. A substantial amount of information is in Spanish, and there is a great deal of information about the institute, its activities and its funding sources. A lot of the original material presented is presented as both patient information and clinician information. A range of treatment options for all cancers is listed, and discussed in some depth, covering risks and benefits, payments, and availability, of treatments. Clinical trials are discussed in depth. Although none of this information is dated and sourced, and no authors are listed, the freely accessible PDQ (Physician Data Query) Database contains peer-reviewed evidence-based summaries (preferably based on RCTs) of prognostic and treatment information supported by references to the source information, with easy-to-read patient-version summaries provides the best information available. The difficulty with this site, as with any comprehensive consumer health web site of any depth, is that the site is overwhelmingly large, and only the most pro-active and persistent consumer would explore the riches it contains. The site does not any quality badges.

Our mission, should we accept it . . .
In summary, none of these sites fully meets all the criteria that we are advocating, to fully cover the principles outlined by the Health on the Net Foundation (HON), the URAC accreditation standards, or DISCERN. It is a 'big ask', as we say, and sites can become cluttered in striving to present all the information that consumers may want. However, by any criteria, using sources such as NOAH, MedlinePlus, and the National Cancer Institute's web site empowers health consumers in a way inconceivable in the past. This is a new and exciting role for health information professionals—to ensure that health consumers know their rights, and are able to find and evaluate high quality health information in order to meet their needs for whatever level of information they seek, and are able, if they choose, to participate in decisions concerning their health and treatment, as 'health-active, health responsible' consumers. It is a challenge taken up by many health information associations, including the Medical Library Association of America, which carries on its web site assistance to consumers in identifying and evaluating web sites. The information it carries would meet some of the learning objectives discussed earlier, and cover criteria listed in some of the 'quality instruments' we have been discussing, though not as thoroughly as this paper suggests is the ideal.

Is this a task for the Health and Biosciences Section of IFLA to undertake, to promote the theme of this year's IFLA Congress, and help all our colleagues in the many countries belonging to our section, to engage in this key role of the health information professional, by developing our own Consumer Health web site and educational resources?

Back to the Programme: http://www.ifla.org/IV/ifla70/prog04.htm