

ABC of health informatics

Is a consultation needed?

Frank Sullivan, Jeremy C Wyatt

People with health concerns no longer have to become patients by consulting a health professional. Electronic health (eHealth) tools provide access to many resources that may satisfy their requirements. This article describes ways that patients can investigate health issues before, or instead of, a consultation.

As a professional, Ms Patel (see box opposite) can access health resources on the internet at work and at home. She may subscribe to a mobile internet service provider through her telephone or palmtop computer. Internet access is not restricted to affluent people in western societies. In the United Kingdom, the 2003 national statistics omnibus survey showed that 48% of households have home internet access, and the figures from the United States are even higher (60% of households have access). Internet cafes can be found worldwide, and library services often provide time online for free. The public can pay for "push technologies" from publishers that supply health alerts, but most people search for the information they need.

Using a search engine

Internet search engines are software tools that index and catalogue websites. People with little or no prior knowledge of a subject, but with some experience of searching the internet, often use search engines to begin an inquiry.

If Ms Patel types "breast cancer and family" into a search engine (such as Google), in 0.23 seconds she may be overwhelmed by more than 5 million websites dealing with the topic. She will be helped by the fact that the search engine has sorted each "hit" by the number of other websites to which it is linked. The list is ordered, and so Ms Patel can start near the top of the list by reading the brief descriptions, or she may use "advanced search" options to narrow the initial search. Advanced searches allow specific phrases, languages, and times to be defined. This reduces the hits to a more manageable number. The most popular sites will probably be those whose content matches patients' preferences for appearance, or those that contain the information patients' are looking for. The most popular sites do not necessarily have features that are the markers of quality preferred by health professionals. If the site does not answer patients' questions, it may provide links to other sites that can. Alternatively, patients can return to the search list and start again.

Patient orientated health portals

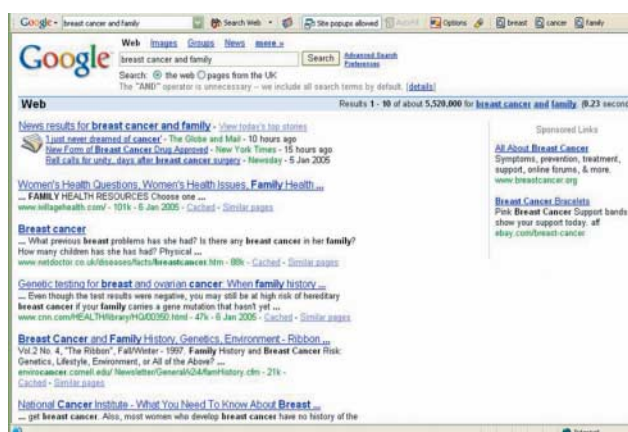
These are specialised search engines with additional features such as access to frequently asked questions about health or email facilities. Individual clinicians, clinics, practices, hospitals, and health maintenance organisations provide portals to their own and other resources.

National and local health services (for example, the NHS in the UK) often provide access to such resources for patients. These portals may link to specific services provided by that health service, such as lists of local cancer genetics clinics.

Other portals are provided by independent bodies. Many have international links and are funded by charities. They vary in quality. Some are quality assured, and when they are not, tools are available to allow patients to assess the portal.

This is the second in a series of 12 articles
A glossary of terms is available at <http://bmj.com/cgi/content/full/331/7516/566/DC1A>

Ms Amulya Patel is a 48 year old accountant whose mother has recently been diagnosed with breast cancer. Ms Patel wonders about her own level of risk, and uses the internet to search for patient resources



Google search results for "breast cancer and family"



An example of a Google hit—sites chosen by patients usually have immediate facts, such as women have a one in eight lifetime risk of developing cancer



NHS Direct is a health portal aimed at the public

Patients make sophisticated use of multiple sources of information. In one study, half of the users of the database of patient experience (DIPEX) who were interested in breast cancer accessed internet resources to obtain second opinions on a range of problems. They sought support and information from patients who had similar issues, obtained information about tests and interventions, and identified questions to ask doctors if necessary.

Many portals link to other websites, and they may direct the person to other resources such as books, multimedia resources, or patient support groups



A relevant health service resource accessed through a portal



DIPEX allows patients (like Ms Patel) to read, listen, or watch patients facing similar problems to their own



Two examples of quality assured portals

Direct access to medical literature

Some health portals link directly to websites that present medical literature intended for professional use. Patients like those in Ms Patel's situation may have gone straight to such resources because they have heard that they will probably contain the information they are seeking. Ms Patel could access primary data sources, such as the *BMJ* or the *Journal of Medical Genetics*, directly. Sometimes journals provide free access to all their content, others make only article abstracts or brief summaries available.

Most patients will have difficulty in interpreting medical journals (as is the case for many doctors). Risk may be described in absolute or relative terms as percentages, rates, multiples, and over different time periods. Because of the complex nature of the articles and papers in medical journals, many people prefer professional help to translate the information that they have found.

Mediated access to medical literature

Several journals have patient orientated summaries that highlight one of their recent scientific papers in a broader context and translate the content into a more readable format. The *New England Journal of Medicine* and *JAMA* are notable in this regard, although subscriptions are needed to access many of these services. Therefore, they may be available only if accessed by the health professional on the patient's behalf.

Jargon may make the information resource impenetrable to non-professionals, and some professionals



Patient summaries in journals can be helpful

Some clinics make questionnaires and guidelines available on their website, but people can find them difficult to interpret. The questionnaire opposite prompts Ms Patel to ask her relatives about the causes of death of other members of her family. She finds that, in addition to her mother, two maternal aunts had breast cancer.

Examples of familial breast cancer management guidelines

Breast Cancer UK Cancer Family Study Group guidelines for referral and screening mammography*

- One relative with breast cancer diagnosed at < 40 years
- Two relatives with breast cancer diagnosed at 40-49 years
- Three relatives with breast cancer who were diagnosed at 50-60 years
- One relative with breast cancer diagnosed at < 50 years, and one or more relatives with ovarian cancer diagnosed at any age, or one relative with breast and ovarian cancer

American College of Medical Genetics/New York State Department of Health candidates for consideration for BRCA1 and BRCA2 testing†

- Three or more affected first degree or second degree relatives on the same side of the family, regardless of age at diagnosis, *or*
- < 3 Affected relatives, but patient diagnosed at ≤ 45 years, *or*
- A family member has been identified with a detectable mutation, *or*
- One or more cases of ovarian cancer at any age, and one or more members on same side of family with breast cancer at any age, *or*
- Multiple primary or bilateral breast cancer in patient or one family member, *or*
- Breast cancer in a male patient, or in a male relative, *or*
- Patient is an increased risk for specific mutation(s) because of ethnic background—for example, Ashkenazi Jewish descent—and has one or more relatives with breast cancer or ovarian cancer at any age

*Eccles D, Evans D, Mackay J. Guidelines for managing women with a family history of breast cancer. *J Med Genetics* 2000;37:2-3-9

†American College of Medical Genetics. Genetics susceptibility to breast and ovarian cancer assessment, counselling and testing guidelines, 1999

Teleconsultation

If the person finds an electronic resource that covers their query, then no consultation may be needed. Often, however, general information will need to be supplemented by knowledge of a person's situation. Ms Patel may email her general practitioner or follow a website link to a specialist in the genetics of familial breast cancer. The advantages of email include asynchronous interaction (patients and doctors can submit and receive responses at their convenience), easy exchange of follow-up information, patient education (by attaching leaflets or links to websites), and automatic documentation of consulting behaviour or service requests. Regulation of teleconsultation varies between countries, and guidelines are available. Security and confidentiality issues must be overcome, and there is increasing pressure to do so. Biometric methods, such as logging in using fingerprints or voice recognition, may be a solution in the medium term. Webcams or other video messaging techniques allow real time, albeit virtual, face to face consultations. To provide teleconferencing, doctors may have to alter their daily schedules.

Summary

Before seeing a doctor, Ms Patel found useful information about familial breast cancer. The information prompted her to ask questions of her family, and she found a strong familial history of breast cancer. She sought professional advice. A computer literate person who wants to find out about a health issue may find a satisfactory answer online, but those who become patients will probably need the expertise from doctors that they trust to interpret data for them.

SAMPLE CANCER FAMILY HISTORY QUESTIONNAIRE

• Name _____

• Date _____

• Age _____

• Ethnic Background [Certain ethnic groups have an increased risk for specific kinds of cancer.] _____

• Do you have any specific concerns about cancer in yourself or your family?

• Do you or any members of your family have a history of cancer?

	Yes/No	Type of Cancer (if known)	Age at Diagnosis (if known)	Living/Deceased
yourself				
your mother				
your father				
your sisters and brothers				
your half sisters and half brothers				
your children				
your mother's sisters and brothers				
your father's sisters and brothers				
your nieces and nephews				
your mother's parents				
your father's parents				

Risk assessment sheet obtained from the internet

Further reading

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The series will be published as a book by Blackwell Publishing in spring 2006.

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