Internet sites of interest

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The experiences of patients, plus a note about cholera

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Here are some sites that contain actual experiences of patients. I have not listed sites that offer patient information (information for patients), or which talk about how to survey the patient experience or use it in planning services.

I am grateful to Outi Pickering of the library at Warneford Hospital, Oxford, for bringing some of these sites to my attention.

All inks were checked on 8th November 2010.

Better Together - Stories
Better Together is NHS Scotland’s patient experience programme. This part of the site enables people to share stories. However, the facility to find stories was not working on the day I checked the link. Hopefully it is by the time you read the column!

Health Talk Online
http://www.healthtalkonline.org/
Health Talk Online contains videos and written information recording experiences of health and illness from more than 2000 people. The site replaces DIPEX, and the information is based on qualitative research undertaken at the University of Oxford. Subjects covered include cancer, dying and bereavement, health disease, pregnancy, later life and young people. A related site at http://www.youthhealthtalk.org/ is aimed at young people and covers cancer, type 1 diabetes, health and weight, epilepsy, sexual health, long term health conditions, and depression.

The Patient Experience
http://www.patient-experience.com/
A discussion forum, provided by The Patients Voice, part of a London based market research company and not to be confused with Patient Voices (see below). There are blogs, video blogs, fact sheets, and information sites.

Patient UK Health Experience Forum
http://experience.patient.co.uk/
A place for people to share experiences. There are currently over 100000, and these can be searched by medical topic or by name of medicine. These experiences also display in the “Your experience” section of Patient UK’s information leaflets.

Patient Voices
http://www.patientvoices.org.uk/
Not to be confused with The Patients Voice (see above), this site aims to facilitate the telling and sharing of patient stories so that those who make policy can hear them. I have to say I did not find the stories easy to locate – I hope the policy makers have more luck. The “Search” facility searches the whole site, not just the stories, and the results page is full of adverts. However, using Find a Story and searching the resulting page for the word I wanted seemed to work.
Other thoughts

Blogging offers an easy way for people to record their health and illness experiences, and so I suspect that a search of the web may also uncover useful material. Google, for one, offers a blog search.

Paying attention to patients’ descriptions of their experiences is a theme in the field of “narrative based medicine”. Although old, this introductory book is still in print:


Columbia University in New York run a program(me) in Narrative Medicine, and there are materials and information at http://www.narrativemedicine.org/. The bibliography (under “Resources”) may lead you to other useful published material.

December 2006’s Internet Sites of Interest column covered Medical humanities, a related area.

A note about cholera

There were outbreaks of cholera in 19th century London, and John Snow’s investigations into their cause are well known. However, in some parts of the world cholera is more than historical. As I write, it is rearing its ugly head in Haiti. Cholera is a bacterial infection that can happen after disasters, as in Haiti, because the bacterium can be found in contaminated water. In severe cases it causes catastrophic dehydration through diarrhoea and vomiting.

Some places to find information on cholera:

Centers for Disease Control and Prevention (CDC)
http://www.cdc.gov/cholera/

Health Protection Agency
http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/Cholera/
The HPA is among the organisations which the UK government wants to close, as part of its cost cutting.

MedlinePlus

ProMed Mail
http://www.promedmail.org/

Todar’s Online Textbook of Bacteriology
http://www.textbookofbacteriology.net/cholera.html
A chapter on Vibrio cholerae and Asiatic cholera.

WHO
http://www.who.int/topics/cholera/en/
CDC, ProMed Mail and MedlinePlus are providing updates on the situation in Haiti.

Information about John Snow:

**John Snow Society**  
[http://www.johnsnowsociety.org/index.html](http://www.johnsnowsociety.org/index.html)  
The Society promotes Snow’s life and works, as well as providing a communication network for epidemiologists.

**Making the Modern World**  
[http://www.makingthemodernworld.org.uk/learning_modules/geography/05.TU.01/?section=2](http://www.makingthemodernworld.org.uk/learning_modules/geography/05.TU.01/?section=2)  
Learning modules based on the Science Museum’s gallery of the same name. Aimed at A level and vocational students.

**UCLA Department of Epidemiology**  
[http://www.ph.ucla.edu/epi/snow.html](http://www.ph.ucla.edu/epi/snow.html)  
An extensive site.

_The column editor writes…_

In the last column I asked if there is still a place for annotated lists of web resources, like this column. Several people contacted me (thank you!) to say that the column was useful to them. I am therefore reassured that the column still has a use.

The column can draw on an individual’s expertise and experience, and bring to light resources that might not appear on the first page of results from an easy but possibly too simple, search of a general search engine. However, it can survive only with your help. I work in a University setting, in medicine, biological science and operating department practice. I see little of the world of the NHS, or of other health professions. The column must have a wide appeal. Can you help stop this column being just a reflection of my own interests? You can, if you are able to contribute lists of resources or suggestions for future columns.

If you feel you can help, please contact me, and thanks!

Finally, reproduction of the contents of this column, with acknowledgement to Health Libraries Group Newsletter, is absolutely fine – please do!

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