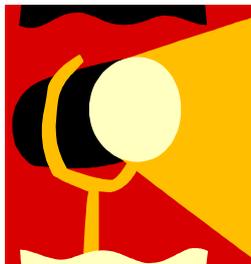


# AIHA Internet Resources Digest

*Supporting Access to High Quality Online Resources*

September 2013



## Spotlight on: PATIENT INFORMATION RESOURCES

**P**atients consistently report wanting more, and better, information about their health,

health care, and treatment options. Evidence suggests that consumers require evidence-based health information to be involved in decision making regarding their health care. Consumer health information is defined as information and support provided to help patients and carers understand, manage and/or make decisions about their health, condition or treatment.

### National and International Initiatives

#### Patient Information Forum



The Patient Information Forum (PiF) is the UK association for professionals that work in the field of consumer health information. On the web-site you can find tools and resources which aim to help you produce, distribute and evaluate high quality consumer health information. Some materials are only available to the members.

<http://www.pifonline.org.uk/>

#### SAFAIDS

The Southern Africa HIV and AIDS Information Dissimination Service

(SAFAIDS), a regional nonprofit organization based in Harare, Zimbabwe, was established in 1994. The organization, in partnership with other non-governmental organiza-



tions, government bodies, and international agencies, disseminates HIV/

AIDS information to the public.

<http://www.saf aids.net/>

#### African Network for Health Knowledge Management and Communication



AfriAfya, African Network for Health Knowledge Management and Communication, is a non-governmental, non-profit organization established in April 2000 by Kenya-based health agencies. AfriAfya Partner agencies are Aga Khan Health Services, AMREF, CARE Kenya, Christian Health Association of Kenya, HealthNet Kenya, Ministry of Health, Plan Kenya and World Vision Kenya. AfriAfya was established to explore practical means of 'harnessing ICT for community health'. It aims to improve health through increasing the availability of relevant up-to-date health information in target communities.

<http://www.afriafya.org/>

## Collections of Resources

### MedlinePlus



One of the leading initiatives in providing web-based consumer health information – is from the US National Library of Medicine: MedlinePlus has extensive information from the National Institutes of Health and other trusted sources on over 900 diseases and conditions.

There are also a medical encyclopedia and a medical dictionary, extensive information on prescription and nonprescription drugs, health information from the media, links to thousands of clinical trials, more than 160 interactive patient tutorials and videos of surgical procedures. MedlinePlus pages also provide links to Patient Handouts. Patient handouts are short, printable lists of tips or

how-tos on dealing with a disease or condition.

MedlinePlus also provides the following types of information resources and tools:

- Easy-to-Read – Health information in plain language
- Games – Boost your health knowledge by playing these interactive health games
- Health Check Tools – Quizzes, calculators, self-assessments, and decision guides to check your knowledge and health status
- Drug Information – Prescription and over-the-counter medicines
- Herbs and Supplements – Evidence-based information about herbs and supplements
- Health Information in Multiple Languages

<http://www.nlm.nih.gov/medlineplus>

### Patient Decision Aids



Patient decision aids are tools that help people become involved in decision making by making explicit the decision that needs to be made, providing information about the options and outcomes, and by clarifying personal values. They are designed to complement, rather than replace, counseling from a health practitioner.

The Patient Decision Aids research program was developed to help patients and their health practitioners make "tough" healthcare decisions. "Tough" healthcare decisions may have many options, uncertain outcomes or benefits and harms that people value differently.

<http://decisionaid.ohri.ca/>

**patientINFORM**

**patientINFORM** is a program that brings together the publishers of the world's leading medical journals and the world's most trusted health organizations to provide patients and their caregivers with access to some of the most up-to-date, reliable and important research available about the diagnosis and treatment of specific diseases.

Publishers who participate in *patientINFORM* help patients access to research in two ways:

- By allowing participating health organizations that create research summaries, news reports or other online analyses to place special links on their sites to the associated research articles in participating journals. These links from the health organizations' web sites provide users with access to the full journal articles free, without subscriptions.
- By providing patients and their caregivers with free or reduced-price access to relevant journal articles through their own web sites.

<http://www.patientinform.org/>

### Health Talk Online - The Database of Individual Patient Experience



Healthtalkonline and its sister website, Youthhealthtalk, let you share in more than 2,000 people's experiences of over 60 health-related conditions and illnesses. You can watch video or listen to audio clips of the in-

terviews, read about people's experiences if you prefer and find reliable information about specific conditions, treatment choices and support.

The information on Healthtalkonline relies on external funding and is based on qualitative research into health experiences, led by experts at the University of Oxford. These personal stories of health and illness will enable patients, families, carers and healthcare professionals to benefit from the experiences of others.

<http://www.healthtalkonline.org/>

### UpToDate Benefits for Patients



Patients can learn more about their medical condition and explore treatment options using UpToDate<sup>®</sup>. After you read the information in UpToDate, you will have the tools to ask the right questions and have important conversations with your health care provider. Simply type your question in the search box below to access the UpToDate free (Beyond the Basics) patient content.

You can look up your specific question — anything from a symptom you're concerned about to a condition or treatment you've been discussing with your health care provider — by typing in a search term like you would using Google.

<http://www.uptodate.com/home/uptodate-benefits-patients>

### AIDSmap



NAM is one of the world's leading sources of independent accurate information on HIV/AIDS.

Treatment and Care Factsheets / Basic illustrated factsheets on the things people might need to know about when they are first diagnosed

<http://www.aidsmap.com/page/1412277/>

Patient Information Booklets provide more detailed information

<http://www.aidsmap.com/page/1412346/>

### HIVInSite – for Patients and Public



HIV InSite is developed by the Center for HIV Information (CHI) at the University of California San Francisco (UCSF), one of the world's leading health sciences institutions.

Information for patients and the public: Expert Advice; Basics; Getting Tested; Just Diagnosed; Treatment Decisions; Living with HIV/AIDS

<http://hivinsite.ucsf.edu/InSite?page=pb-00-00>

### Consumer Health Information in Many Languages Resources



Collection of links to online resources in different languages. Compiled by NN/LM Consumer Outreach Librarians.

<http://nnlm.gov/outreach/consumer/multi.html>

## Guides

### A Consumer's Guide to Taking Charge of Health Information



Most people are on their own as they evaluate health information, put it into context, and make important health care decisions for themselves and their families. This requires an understanding of the concept of risk. Risk is important because it implies that there is some *chance* that something bad *might* happen. The uncertainty can be frustrating and frightening, but it also means that your attitude and choices can play a major role in your future health. Check out a list of 10 questions designed to help you turn health information into clues.

<http://www.health-insight-harvard.org/>

### Evaluating Web-sites for consumer health information

Points to consider when evaluating Internet sites for consumer health information. Provided by Connecticut Consumer Health Information Network.

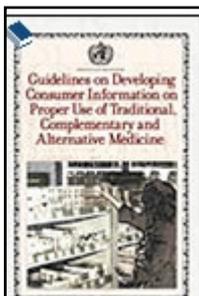
<http://library.uhc.edu/departm/hnet/rbevalwebsite.html>

### A User's Guide to Finding and Evaluating Health Information on the Web



This guide outlines the collective wisdom of medical librarians who surf the web every day to discover quality information in support of clinical and scientific decision making by doctors, scientists, and other health practitioners. <http://www.mlanet.org/resources/userguide.html#3>

### WHO Guidelines on Developing Consumer Information on Proper Use of Traditional, Complementary and Alternative Medicine



These guidelines are intended to provide technical guidance in order to assist Members States in developing context-specific and reliable consumer information promoting proper use of traditional medicine and

complementary and alternative medicine. 2004. 109 pp

<http://apps.who.int/medicinedocs/en/d/Js5525e/>

### Developing Materials on HIV/AIDS/STIs for Low-Literate Audiences

The guide provides a comprehensive methodology for developing materials for low-literate audiences in the context of a strategic behavior change (SBC) program.

<http://www.fhi360.org/en/HIVAIDS/pub/guide/lowliteracyguide.htm>

### Managing a Consumer Health Information Service (CHIS)

Current recommendations and bibliographies for all aspects of creating and managing consumer health information services, including planning, funding, promotion and evaluation.

<http://caphis.mlanet.org/>  
[http://caphis.mlanet.org/chis/patient\\_ed.html](http://caphis.mlanet.org/chis/patient_ed.html)

### Producing information about health and health care interventions: a practical guide

This guide from Aberdeen University gives ideas and practical advice for producing good quality information materials (leaflets, audiotapes, videos etc) about health and health care interventions for patients and members of the public. Includes a section on information needs and gaps in research evidence.

[http://www.abdn.ac.uk/hsrc/documents/revisedguide\\_090603.pdf](http://www.abdn.ac.uk/hsrc/documents/revisedguide_090603.pdf)

### Patient Information Toolkit



Produced by the UK Department of Health (National Health Service/NHS). The toolkit includes guidance on how to produce written information for patients and a series of templates to make it easier to produce good-quality information for patients and assess how it is used. <http://www.nhsidentity.nhs.uk/page/5287>

### The Case for Information: Investment in patient information improves outcomes and reduces costs.

Patient Information Forum (PiF) research report highlights how providing information to patients and their carers improves outcomes, reduces costs and gives people a better experience of care. 2013

<http://www.pifonline.org.uk/case-full-report>

### AIHA Internet Resources Digest Forthcoming Topics [Provisional]

- Telemedicine
- Disaster Medicine

## AIHA Related Resources

**Shared Decision Making.** *Internet Resources Digest, April 2013*

[http://www.healthconnect-intl.org/files/ir-bulletin/IRD\\_Apr13.pdf](http://www.healthconnect-intl.org/files/ir-bulletin/IRD_Apr13.pdf)

### About the AIHA Internet Resources Digest

The *Internet Resources Digest* — previously called the *Health Resources Digest* — is distributed free of charge as a service of the American International Health Alliance's Learning Resources Project thanks to the generous support of the American people through the US President's Emergency Plan for AIDS Relief (PEPFAR). The Learning Resources Project is implemented through AIHA's HIV/AIDS Twinning Center Program, which is funded through a cooperative agreement with the US Department of Health and Human Services, Health Resources and Services Administration (HRSA).

The *Internet Resources Digest* is compiled by Irina Ibraghimova, PhD, Library and Information Management Specialist HealthConnect International ([www.healthconnect-intl.org](http://www.healthconnect-intl.org)). The contents are the responsibility of AIHA and do not necessarily reflect the views of PEPFAR, HRSA, or the United States Government.

If you have a suggestion for a Digest topic, or would like to contribute information about Internet resources, please contact [ibra\[at\]zadar.net](mailto:ibra[at]zadar.net).

Back issues of the *Internet Resources Digest* for 2011-2013 are archived at [www.healthconnectintl.org/resources.html](http://www.healthconnectintl.org/resources.html).

If this document is to be redistributed or posted on another Web site, we request that it be posted in full without alteration, and credit is given to the AIHA as the source of the document.

