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SCOPE NOTE

Bioethics Resources on the Web

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Introduction (June 2000)

Once described as an "enormous used book store with volumes stacked on shelves and tables and overflowing onto the floor" (Pool, Robert. 1994. Turning an Info-Glut into a Library. *Science* 266 (7 October): 20-22, p. 20), Internet resources now receive numerous levels of organization, from basic directory listings to elaborate "links" (cross-references to other Internet documents) that flash and glow in the dark. In many ways, the Internet functions as a direct extension of the traditional library. Following linked references across various sites is an electronic version of

browsing library stacks, and the serendipitous discoveries made while "surfing the Net" recall the wonders of physically going "book-to-book." Although many of the Internet's best aspects augment library strengths by eliminating physical distance from sources, Net resources pose unique problems for researchers. It is not always clear who is responsible for the content of Web documents, when the document was produced, or how often (if ever) it is updated. Internet resource tools, then, must enable researchers to identify appropriate resources and to evaluate what they find when they get there.

Web Research as Taking "SNAPSHOTS"

Given the Internet's visual nature and fluid content, the process of conducting research on the Web has been likened to taking an informal picture of information on a specific date at a particular time. This metaphor also conveys the "zoom-in" aspect of searching through Web pages by going from general to specific categories. In the first section of this *Scope Note*, National Reference Center for Bioethics Literature (NRCBL) staff present a snapshot of bioethics resources originally taken during the spring months of 2000 and updated periodically since then. Entries are divided into the categories of directories, electronic journals, full-text documents, news/current awareness, and teaching resources. In the two subsequent sections, this series of categories is repeated for entries on a specific topic within bioethics–genetics–and again for general search and evaluation tools. Where a Web site may contain pages applicable to more than one category, multiple entries are made for that site with appropriate information for each category.

Much as telecommunication advances have strengthened the relationship of patients and providers as partners, the dynamic nature of the Internet acknowledges that the researcher functions as a librarian whenever accessing the Web. It is our hope that NRCBL resources not only will enable researchers to search the Web more efficiently, but also will help them to evaluate what they find when they get there.

Bioethics in Databases on the Web

From 1973 to 2000, the Kennedy Institute of Ethics produced BIOETHICSLINE® for the U.S. National Library of Medicine (NLM) as one of their specialty MEDLARS databases designed to supplement MEDLINE. In 2001, NLM reorganized its databases: journal records from all specialty databases were merged with MEDLINE into PubMed, and book records were combined with NLM's online catalog to create LOCATORplus. Both of these databases can be searched at no charge either separately or through NLM's Gateway.

The inclusion of bioethics citations in PubMed and LOCATORplus has several advantages. First, unique keywords from the former Bioethics Thesaurus have been included in Medical Subject Headings (MeSH), the indexing vocabulary for PubMed and LOCATORplus, thereby enhancing retrieval of relevant clinical literature by offering more precise terminology covering ethical issues. Second, there is extensive coverage of foreign-language materials in NLM databases. Third, NLM databases are updated daily.

The online catalog for the National Reference Center for Bioethics Literature (NRCBL) <u>EthxWeb</u>, contains citations to journal articles, books and book chapters, Web documents, audiovisuals, conference proceedings, and unpublished documents. NRCBL provides reference assistance and searches of these databases at no charge; requests can be made by submitting an <u>online search form</u>.

The Web brings all of us closer together, giving us opportunities to examine approaches to bioethical problems in other countries. The Web pages of organizations can be consulted for pertinent documents. On a broader level, some government and academic groups are supporting the collection and dissemination of bioethics resources worldwide. (Note: many have adopted the vocabulary of the former Bioethics Thesaurus as the basis for developing their own indexing languages. The thesaurus has been translated into Dutch, French, German, Spanish, and Swedish, and a Turkish translation is underway. Often the vocabulary is enhanced to reflect varying local social, cultural, legal, and philosophical perspectives.)

Cooperative programs, such as that between the Kennedy Institute and the Deutsches Referenzzentrum für Ethik in

den Biowissenschaften (DRZE) in Bonn (http://www.drze.de) to share bibliographic data, will further enhance the retrieval of bioethics literature internationally. DRZE and other similar centers in Germany and Europe are working to make databases and online library catalogs available. The Akademie für Ethik in der Medizin, George-August-Universität in Göttingen, Germany, an organization with a long-standing interest in bioethics documentation, added 5,570 documents to the ETHMED database from 1994 through March 1999 (http://www.aem-online.de/main.htm). NRCBL will continue to provide links to these and to other bibliographic resources at: http://bioethics.georgetown.edu.

The Categories:

Directories, Electronic Journals, Full-Text Documents, News/Current Awareness, and Teaching Resources

Reference requests received at NRCBL have informed our choice of the categories used to organize this <u>Scope Note</u>. Online directories meet the needs of those who ask "Where do I start?" Directories are lists of resources accompanied by their links and, sometimes, by brief summaries. In many ways, the home pages of bioethics organizations, with their extensive collection of links, function as directories for both the novice and expert searcher.

Electronic journals are at once the boon and the bane of Internet existence. When we can access the latest issues of major journals on the Web while the print copies are still in the mail, we cannot imagine how we ever functioned without the Internet. When access to the electronic version of a journal is limited to an institutional subscription not taken by our university, we fear that the Web may actually restrict rather than expand access to resources. The Internet's initial reputation of being "free" to all is changing rapidly. To provide local access to electronic journals, many publishers provide institutions with site licenses for the electronic versions of their journals. One example is Johns Hopkins University Press's "Project Muse," which provides electronic access to journals, including the *Kennedy Institute of Ethics Journal*, through institutional site licenses (http://muse.jhu.edu/journals/ken).

To determine which electronic journals you can access, first check with your local reference librarian. Second, lists of electronic journals are maintained on the Web (see the electronic journals part of each of the following sections). For medical journals, PubMed contains links to records in the National Library of Medicine's online archive, PubMed Central. In addition, publishers may provide links to the full-text of their journals for a specified period (see below, Evaluation and Searching Tools, Electronic Journals, HardinMD Electronic Showcase). If a publisher does not participate in direct links from PubMed, NLM's Loansome Doc document delivery service enables searchers to place online orders for copies of articles.

The posting of full-text documents on the Internet is growing as a result of improvements in Web design software and server storage capacity. National Digital Library projects are underway at various government agencies (http://www.osti.gov/inforum2000/) in the United States, and bioethics commissions, both in the U.S. and abroad, concentrate on making their reports available full-text.

Building on an original strength of the Internet, rapid communication among researchers and other groups is enhanced by online discussion groups and by electronic mailing lists commonly called "listservs" for list servers. Searchable listserv archives are a valuable and frequently overlooked research tool. For meeting and conference information, bioethics organizations often maintain listings of local events, and for international coverage many link to the International Calendar of Bioethics Events (see below, Bioethics on the Web, News/Current Awareness--Bioethics).

Teaching resources on the Web can either facilitate the preparation of course materials, or serve as course materials themselves. Syllabi for some courses go beyond the usual outline and bibliography to include links to full-text documents and online videos. As with libraries, the Internet can act both as an extension of the classroom and as a unique learning environment of its own. The effect of cyberspace on learning and on research is unclear, but with the development of evaluation criteria for Web sites, a critical stance toward information sources becomes the common ground for the further elaboration of all research and study.

BIOETHICS - GENERAL

Directories

Site: **ASBH**

Organization: American Society for Bioethics and Humanities (ASBH)

Location: Glenview, IL Country: United States WWW: http://www.asbh.org

As the professional society for bioethics, ASBH's site provides information about their reports, books and newsletter, including a link to the report of the <u>ASBH Task Force on Ethics and Humanities Education in Undergraduate Medical Education</u> (2009).

Site: Association for Practical and Professional Ethics (APPE)

Organization: Indiana University Location: Bloomington, IN Country: United States

WWW:http://www.indiana.edu/~appe/

As a membership organization devoted to the interdisciplinary study and teaching of practical and professional ethics, APPE's site focuses on descriptions of its programs such as Ethics Bowl and the Pre-College Ethics Interest Group, as well as posting job announcements and grant opportunities.

Site: <u>Bioethics Resources on the Web</u>
Organization: National Institutes of Health
Inter-Institute Bioethics Interest Group (BIG)
Office of Extramural Research (OER)

Location: Bethesda, MD Country: United States

WWW: http://bioethics.od.nih.gov/

NIH's bioethics portal organizes its resources into the following categories: Bioethics and the NIH, General Resources, Organizations of Interest, Other Federal Resources, and Specific Topics (Research Ethics, Genetics, and Medicine and Health Care).

Site: Center for Bioethics Resources & Links

Organization: University of Minnesota

Center for Bioethics

Location: Minneapolis, MN Country: United States

WWW: http://www.ahc.umn.edu/bioethics/resource/home.html

Along with an Aask an ethics question@ feature, the Center for Bioethics web site provides summaries and overviews of bioethical issues, links to full-text bioethics documents (such as the Minnesota Health Care Directives form), and hosts the EthicShare database and web site (https://www.ethicshare.org/).

Site: Global Ethics Observatory (GEObs)

Organization: United Nations Educational, Scientific and Cultural Organization (UNESCO), Social & Human

Sciences, Ethics of Science and Technology

Location: Paris

Country: France

WWW: http://www.unesco.org/shs/ethics/geobs/

UNESCO's Global Ethics Observatory (GEObs) consists of six databases available in UNESCO's six official languages: Arabic, Chinese, English, French, Russian and Spanish: Who's Who in Ethics, Ethics Institutions, Ethics Teaching Programs, Legislation and Guidelines, Codes of Conduct, and Resources in Ethics. An interactive geographical search feature is provided to retrieve all information by region or country.

Site: Interfakultären Zentrum für Ethik in den Wissenschaften / Interdepartmental Center for Ethics in the Sciences and Humanities (IZEW)

Organization: University of Tübingen, Interdepartmental Center for Ethics in the Sciences and Humanities

Location: Tübingen Country: Germany

E-mail: <u>izew@uni-tuebingen.de</u>

WWW: http://www.izew.uni-tuebingen.de

This site provides access to the catalog for the libraries of the IZEW and their Chair for Ethics in the Life

Sciences.

Site: National Reference Center for Bioethics Literature (NRCBL)

Organization: Kennedy Institute of Ethics

Georgetown University Location: Washington, DC Country: United States

WWW: http://bioethics.georgetown.edu

The bioethics library site provides access to and instructions for searching the following databases:

EthxWeb - bibliographic citations of bioethics and professional ethics literature;

GenETHX - bibliographic citations of literature on genetics and ethics;

Syllabus Exchange - bioethics syllabi for courses from high school through graduate education, with links to the full-text of each syllabus available online;

International Bioethics Organizations - bioethics organizations from around the world; and

Bioethics Thesaurus - keywords in the controlled subject vocabulary used for indexing the bioethics literature.

NRCBL's site also provides searchers with the opportunity to automatically generate bibliographies on specific topics and request customized reference service.

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Electronic Journals

Site: <u>Bioethics Journal Resources on the Web</u> Organization: National Institutes of Health Inter-Institute Bioethics Interest Group (BIG)

Office of Extramural Research (OER)

Location: Bethesda, MD Country: United States

WWW: http://bioethics.od.nih.gov/bioethicsjournals.html

This listing links to specific journal homepages and databases.

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Full-Text Resources

Site: Council of Europe, Bioethics Home Page

Organization: Council of Europe

Directorate of Legal Affairs, Bioethics Section

Location: Strasbourg Country: Austria

WWW: http://www.coe.int/t/dg3/healthbioethic/texts_and_documents/default_EN.asp

This site contains the compendium of texts of the Council of Europe on bioethical matters along with the

full-text of *The Convention on Human Rights and Biomedicine*,

(http://conventions.coe.int/Treaty/EN/Treaties/html/164.htm) and documents related to its preparation.

Site: National Consultative Ethics Committee for Health and Life Sciences

Organization: French National Consultative Ethics Committee for Health and Life Sciences

Location: Paris Country: France

E-mail: contact@comite-ethique.fr WWW: http://www.ccne-ethique.fr

The full-text of all the opinions of the French national bioethics commission, beginning with #001 in 1984,

are available in both French and English.

Site: Eubios Ethics Institute

Organization: Eubios Ethics Institute

Location: Bangkok Country: Thailand

E-mail: <u>asianbioethics@yahoo.co.nz</u> WWW: <u>http://www.eubios.info</u>

This site links to e-books on Asian bioethics, teaching guides, and historical documents relating to the Eubios

Ethics Institute.

Site: Library of Bioethics and Medical Humanities Texts and Documents

Organization: University of Buffalo, Center for Clinical Ethics and Humanities in Health Care

Location: Buffalo, NY Country: United States E-mail: <u>ifreer@buffalo.edu</u>

WWW: http://wings.buffalo.edu/faculty/research/bioethics/texts.html

This electronic library features classic bioethics texts such as *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects in Research*, encyclicals of the Roman Catholic Church on bioethical issues, and the *Advisory Committee on Human Radiation Experiments: Final Report*. The site also

links to bioethics reports from state and federal agencies.

Site: National Bioethics Advisory Commission

Organization: National Bioethics Advisory Commission (NBAC) (defunct)

Location: Rockville, MD Country: United States

WWW: http://bioethics.georgetown.edu/nbac/

NBAC was established by a Presidential executive order in 1995; its charter expired on October 3, 2001.

NBAC's reports and meeting transcripts are archived and available full text on the site of the National

Reference Center for Bioethics Literature.

Site: Nuffield Council on Bioethics

Organization: Nuffield Council on Bioethics

Location: London Country: Great Britain

WWW: http://www.nuffieldbioethics.org

The full text of the Council=s reports and discussion papers are provided along with drafts of works-in-

progress.

Site: Online Ethics Center at the National Academy of Engineering [OEC]

Organization: National Academy of Engineering

Location: Washington, DC Country: United States

WWW: http://www.onlineethics.org/

Focusing on science and technology, OEC's site contains essays, case studies, articles, guidelines, and teaching materials on ethical issues with environmentalism, professionalism, research, technological, and

business.

Site: OTA Legacy

Organization: Princeton University

Location: Princeton, NJ Country: United States E-mail: ota@princeton.edu

WWW: http://www.princeton.edu/~ota/

This electronic archive of the publications of the Congressional Office of Technology Assessment [OTA] (which closed on September 29, 1995) also contains a history of the OTA and full-text articles on its

importance.

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News/Current Awareness

Site: Bioethics and Today's News

Organization: The Johns Hopkins University, Bioethics Institute

Location: Baltimore, MD Country: United States

WWW: http://www.bioethicsinstitute.org/

The Bioethics Institute home page features links to recent news stories and blog postings on bioethical issues.

Site: Bioethics Discussion Pages

Organization: University of Southern California, Health Sciences Center

(Personal Home Page of Dr. Maurice Bernstein)

Location: Los Angeles, CA Country: United States E-mail: DoktorMo@aol.com

WWW: http://www-hsc.usc.edu/~mbernste/

Moderated by Maurice Bernstein, M.D., this site features a general discussion group entitled "Pot-Pourri," discussion pages for specific topics, and polls on various ethical issues prompted by topics raised by participants. Recently modified entries are highlighted with a balloon icon.

Site: **Bioethics.Net**

Organization: University of Pennsylvania

Center for Bioethics

Location: Philadelphia, PA Country: United States

WWW: http://www.bioethics.net

In addition to featuring its publication *American Journal of Bioethics*, this site links to resources on bioethical issues, online news stories and blog postings as well as its own blog (http://blog.bioethics.net).

Teaching Resources

Site: Ethics Committee Core Curriculum
Organization: University of Buffalo

Center for Clinical Ethics and Humanities in Health Care

Location: Buffalo, NY Country: United States

WWW: http://wings.buffalo.edu/faculty/research/bioethics/

This site contains the electronic version of Western New York Institutional Ethics Committee Network's

Orientation Manual for Ethics Committee Members.

Site: Ethics Updates

Organization: University of San Diego

Values Institute

Location: San Diego, CA Country: United States

WWW: http://ethics.sandiego.edu

Focusing on resources for ethics instruction, this site contains links by to videos, full-text articles, and other websites for both ethical theory and applied ethics topics. Discussion questions are included for each section.

Site: Medical Humanities Syllabi, Hippocrates Project

Organization: New York University Department of Medical Humanities

Location: New York, NY Country: United States

WWW: http://medhum.med.nyu.edu/syllabi.html

This collection of full-text syllabi is organized by both topic and institution.

Site: Syllabus Exchange Database

Organization: National Reference Center for Bioethics Literature,

Kennedy Institute of Ethics Georgetown University Location: Washington, DC Country: United States

E-mail: bioethics@georgetown.edu

WWW: http://bioethics.georgetown.edu/databases/syllabus/

This database contains records for over 600 syllabi in 3 languages from 12 countries dating from the early 1980s to the present. Each record is linked to the full-text of the syllabus.

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GENETICS SNAPSHOT

Directories

Site: Council for Responsible Genetics (CRG)
Organization: Council for Responsible Genetics

Location: Cambridge, MA Country: United States Email: crg@gene-watch.org

WWW: http://www.councilforresponsiblegenetics.org

In addition to providing access to their newsletter, *GeneWatch*, and its archives, CRG links to position papers, reports and full-text articles on it current projects: Race and Genetics, Forensic DNA, Gene Myths, the Genetic Bill of Rights. Also available are CRG's resource pages for their previous projects, such as genetic determinism and biowarfare.

Site: DOEgenomes.org

Organization: U.S. Department of Energy Office of Science

Location: Washington,DC Country: United States

WWW: http://genomics.energy.gov

This gateway facilitates access to Human Genome Project educational and archival documents, materials produced by Genomics.GTL (systems biology for energy and the environment), and information concerning Microbial Genome Project.

Site: GeneTests

Organization: National Center for Biotechnology Information, National Institutes of Health

Location: Bethesda, MD Country: United States

WWW: http://www.genetests.org

This site provides access to a database of genetic testing clinics and laboratories that is international in scope. Also included are patient education materials on various genetic diseases, and a glossary of terms.

Site: genome.gov

Organization: National Human Genome Research Institute (NHGRI), National Institutes of Health

Location: Bethesda, MD Country: United States

WWW: http://www.genome.gov

As the site for the completed Human Genome Project, NHGRI's genome.gov

features links to the continuing international genome sequencing programs, clinical research centers, and Ethical, Legal and Social Implications Program (ELSI) projects and publications. One ELSI project is the Policy and Legislation Database containing the full-text of federal and state regulations on such issues as genetic testing, patenting, informed consent and confidentiality.

Site: GeneWatch UK

Organization: GeneWatch UK Location: Buxton, Derbyshire

Country: Great Britain

WWW: http://www.genewatch.org

GeneWatch UK provides overviews of such topics as genetically-modified crops and animals, genetic patents, and forensic DNA, and augments these essays with links to reports and articles on each topic.

Site: Public Health Genomics

Organization: Office of Public Health Genomics (OPHG), Centers for Disease Control and Prevention (CDC), U.S.

Department of Health and Human Services

Location: Atlanta, GA Country: United States

WWW: http://www.cdc.gov/genomics/

This site focuses on CDC reports and resources on such topics as translational genomic research, genetic testing, and population research.

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Electronic Journals

Site: Genome Medicine

Organization: BioMed Central: The Open Access Publisher

WWW: http://genomemedicine.com

Genome Medicine is a free, open access journal devoted to all aspects of genetic research. Users can sign up for email alerts of newly published articles.

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Full-Text Resources

Site: **DOE Information Bridge**

Organization: Department of Energy

Office of Scientific and Technical Information

Location: Oak Ridge, TN Country: United States

WWW: http://www.osti.gov/bridge/

This site provides links to the free full-text of over 210,000 DOE-sponsored reports on genetic research

published since January 1995

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News/Current Awareness

Site: Forum Gentechnik

Organization: University of Tübingen

Interfaculty Center for Ethics in the Sciences and Humanities

Location: Tübingen Country: Germany

WWW: http://www.zum.de/zum/Foren/biotech/cgi/forum.cgi

This forum is a discussion group for scientists to exchange information on genetics research.

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Teaching Resources

Site: Dolan DNA Learning Center

Organization: Cold Spring Harbor Laboratory

Location: Cold Spring Harbor, NY

Country: United States

WWW: http://www.dnalc.org

In addition to animated educational materials on molecular biology, this site contains an image archive of the American eugenics movement as well as simulated gene sequencing exercises..

Site: Human Genome Project Education Resources

Organization: Human Genome Project

Department of Energy Location: Oak Ridge, TN Country: United States

WWW: http://www.ornl.gov/sci/techresources/Human Genome/education/education.shtml

As part of the U.S. Department of Energy's genome gateway, <u>DOEGenomes.org</u>, this page contains full-text documents such as *Genomics and Its Impact on Science and Society: The Human Genome Project and Beyond* and *Your Genes, Your Choices*, as well as the *Genome Education Modules* produced as part of the Biological Sciences Curriculum Study (BSCS). Also included are video and audio files (PBS) that can be

downloaded for educational purposes, and the archives of their *Human Genome News* newsletter.

Site: National Information Resource on Ethics and Human Genetics
Organization: National Reference Center for Bioethics Literature

Kennedy Institute of Ethics Georgetown University Location: Washington, DC

WWW: http://genethx.georgetown.edu

This site contains annotated bibliographies on genetic topics, full-text government reports and historic documents on ethics and genetics, and searchable databases of literature on ethics and genetics, and DNA

patents.

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EVALUATION AND SEARCHING TOOLS

Electronic Journal Lists

Site: Periodici Biomedici/Biomedical Journals

Organization: Biblioteca Centrale dell'Area Biomedica

Università degli Studi di Cagliari Cittadella Universitaria di Monserrato

Location: Monserrato

Country: Italy

WWW: http://aib.it/aib/commiss/cnur/peb/peb.htm3

This comprehensive list of international journals identifies whether the specified links access a periodical's table of contents pages, the full-text of sample articles, or the full-text of the entire publication. The site also contains links to electronic journal directories for other countries, such as France and Germany.

Site: HardinMD E-journal Showcase

Organization: Hardin Library for the Health Sciences

University of Iowa Location: Iowa City, IA Country: United States

WWW: http://www.lib.uiowa.edu/hardin/md/ej.html

This directory of electronic journals serves two purposes: to link to the electronic version of popular peerreviewed medical journals such as *JAMA* and *BMJ*, and to display the previous year's citations from each electronic journal that have appeared in the PubMed database.

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Full-text Resources

Site: The Charters of Freedom

Organization: National Archives and Records Administration

Location: Washington, DC Country: United States

WWW: http://www.archives.gov/exhibits/charters/charters.html

The National Archives and Records Administration has the full text of the Declaration of Independence, the United States Constitution, the Bill of Rights, and the Constitutional Amendments. Highlighting has been used to indicate passages that have been superseded or repealed, thus making the documents current.

Site: Thomas — Legislative Information on the Internet

Organization: Library of Congress

Location: Washington, DC Country: United States WWW: http://thomas.loc.gov

This site permits the monitoring of current legislation and contains links to historical documents and the full-

text legislative sites for the Executive and Judicial branches of the federal government.

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Teaching Resources

Site: HON Code of Conduct (HONcode) for Medical and Health Web Sites

Organization: Health on the Net (HON) Foundation

Location: Geneva Country: Switzerland

WWW: http://www.hon.ch/HONcode/Conduct.html

Originally published in July 1996, the HONcode has been amended and expanded to eight principles, which are published on the site in 11 languages. The code addresses: "authority of the information, data confidentiality and privacy, proper attribution of sources, transparency of financial authorship," and the clear separation of advertising from editorial content.

Site: Information Quality WWW Virtual Library

Organization: Asia Pacific Research Online

Location: Research School of Asian and Pacific Studies (RSPAS)

Australian National University, Canberra,

Country: Australia

E-mail: tmciolek@ciolek.com

WWW: http://www.ciolek.com/WWWVL-InfoQuality.html

This site is a directory of links to reports, articles, publishing guides, and evaluation standards for developing, maintaining, and assessing information on the Internet. Of special interest is the site's annotated bibliography *Evaluation of Information Sources*.

Site: Trust It or Trash It?
Organization: Genetic Alliance
Location: Washington, DC
Country: United States

WWW: http://www.trustortrash.org

This online reference tool was designed by the Genetic Alliance, a consumer advocacy group, to enable the public to evaluate the quality of online genetic information.

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