

Finding what you need?

Information resources for international research ethics

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IU Center for Bioethics

Teaching Skills in International Research Ethics (TaSkR) III

Indianapolis, Indiana

April 13, 2011

Bioethics Reference Center

Serving Indiana University and our collaborators (if you're listening to this, that means you) with:

Website - <http://bioethics.iu.edu>

Email - jdodell@iupui.edu

- a small, non-circulating print collection (~1,000 volumes)
- a growing digital collection
- online information tools
- in-depth reference support

INDIANA UNIVERSITY CENTER FOR BIOETHICS

Department of Medicine | ISM | EPLR | Contact Us

HOME
ABOUT
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NEWS
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PUBLICATIONS
REFERENCE CENTER

Belmont Revisited
Ethical Principles for Research with Human Subjects
James F. Childress, Eric M. Meslin, and Harold T. Shapiro, Editors

Bioethics Reference Center
The Bioethics Reference Center, a non-circulating branch of the Ruth Lilly Medical Library, provides in-depth reference support for your bioethics research needs.

Welcome
The Center is recognized throughout the state and around the globe as a primary source for bioethics research and new information. Research addresses ethical, legal, and social issues in healthcare and science with an emphasis on multidisciplinary approaches. Topics range from genetics to organ transplantation, medical research to health privacy, informed consent to pandemic flu preparedness.

Programs
[Biogenics and Subject Advocacy \(BSA\)](#)
[Center for Law, Ethics, and Applied Research \(CLEAR\) in Health Information](#)
[IU-MIU Academic Research Ethics Partnership](#)
[Predictive Health Ethics Research \(PHER\)](#)

Featured
Register Now for the Teaching Skills in International Research Ethics ("TeSkill") Workshop: April 12 - 14 - [PDF - 234 KB](#)
Biobanks, Genetic Research and Ethics: Publications - [PDF - 110 KB](#)
PredictOR Schedule - [PDF - 74 KB](#)
Seminars in Medical Humanities - [PDF - 328 KB](#)
[PredictOR Law and Policy Updates](#)
[Bioethics Subject Guide](#)

News & Events
> From Laboratories to Legislatures: Can a Translational Approach to Science Policy Bridge Its "Valley of Death"?
April 1st
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> Ethics and privacy considerations for systems biology applications in predictive and personalized medicine [PDF]
March 20th
[read story...](#)
> Kenya Research Ethics Bibliography
March 23rd
[read story...](#)
> Sound Ethics: Synthetic Biology
March 22nd
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Preview

1. Refresher: basic tools and techniques in online searching for ethics literature
2. Access: finding free full text?
3. Search Demo (if we have time)
4. Questions

Basic Search Tools

1. **Use your library!**
2. **Use at least 3 tools** - a good mix might include:
 - a. Encyclopedia or topical website
 - b. Book or article database
 - c. Web search engine
3. **Use reference management and “bookmarking” services;** some examples:
 - a. Zotero (free)
 - b. EndNote; RefWorks; Reference Manager - (free at some universities)
 - c. CiteULike (free)
 - d. Delicious, Diigo, etc (mostly free)

Resources for Bioethics Information at IUPUI

1. **Books:** Use IUCat to find books in any IU campus library - <http://iucats.iu.edu/>
2. **Articles:** Use the Medical School Library subject guide to select a good subscription database for bioethics literature – <http://library.medicine.iu.edu/bioethics>
3. **Websites:** Use IUCB's International Research Ethics subject guide to find Web-based resources – <http://bioethics.iu.edu/ireguide>
4. **Search tutorials and tips:** I have uploaded this presentation and others to our website. See: <http://bioethics.iu.edu/finding>

Free Resources for International Research Ethics:

3 Web Guides

- Fogarty International Center, NIH: **International Research Ethics Resources** - http://www.fic.nih.gov/programs/training_grants/bioethics/resources.htm
- IUCB: **International Research Ethics Subject Guide** - <http://bioethics.iu.edu/ireguide>
- CGS: **Project for Scholarly Integrity** - <http://www.scholarlyintegrity.org/>

3 Search Engines and Portals

- **EthicShare** – <http://www.ethicshare.org>
- **Globethics.net** - <http://www.globethics.net>
- **Google** - <http://www.google.com/> (use the Boolean and Advanced search options)

Free Resources for International Research Ethics:

3 Databases and Academic Search Tools

- PubMed Medline: <http://pubmed.gov>
- Google Scholar: <http://scholar.google.com/>
- NRCBL ETHXweb: <http://bioethics.georgetown.edu/>

3 Library Catalog Tools

- Google Books: <http://books.google.com>
- National Library of Medicine, U.S.: <http://www.nlm.nih.gov/>
- WorldCat: <http://www.worldcat.org/>

Basic Search Tips

- 1. Develop a search strategy**
 - a. List the key terms and concepts of your question
 - b. Make a list of tools to try
 - c. Start with overviews (encyclopedias, books, lit. reviews) and move to specifics (articles, policies, commentaries)
- 2. Choose your tools according to your needs**
- 3. Use a variety of search skills**
 - a. Boolean and phrase searching
 - b. Controlled vocabularies
 - c. Citation chaining
 - d. Subject, TOC and author browsing
- 4. Don't forget networking**
- 5. "Research is re-searching"**

The “well-built” ethics question?

P I [E S]

Patient or population

Who? (age, gender, ethnicity, disease or health status, religion, occupation, etc.)

Where? (North America, Indiana, developing countries, etc.)

Intervention or exposure

C-Section? Insulin? Anti-depressants? Exercise? Genetic test? Colonoscopy?

*** Ethical issue or concept**

Autonomy, Beneficence, Nonmaleficence , Justice; Informed consent, Privacy, Advanced directives, Discrimination, Trust, and more ...

*** Source or document type**

Case study? Review article? Book? Commentary? Empirical study? Professional guideline? Government policy or legislation? Legal decision?

***Often the more important features of an interdisciplinary, ethics search.**

Note: this approach is based on: *Construct well-built clinical questions using PICO.*

University of Washington Health Sciences Libraries. Accessed 14 April 2009 from

<http://healthlinks.washington.edu/ebp/pico.html>

piEs: Build your **ethics** vocabulary

If you or your students are new readers of the ethics literature, consult a few free sources to find useful search terms:

Vocabularies:

- NRCBL, **Bioethics Thesaurus Database**:
<http://bioethics.georgetown.edu/databases/bt/>
- **MeSH**, NLM Controlled Vocabulary: <http://www.ncbi.nlm.nih.gov/mesh>
- BELIT-DRZE, **Bioethics Thesaurus**: <http://www.drze.de/bioethics-thesaurus>

Ethics encyclopedias or websites (3 examples of free resources):

- **Ethics in Medicine**, University of Washington School of Medicine: Bioethics Topics – <http://depts.washington.edu/bioethx/topics/>
- NRCBL, **Scope Notes Series**:
<http://bioethics.georgetown.edu/publications/scopenotes/>
- **Stanford Encyclopedia of Philosophy**: <http://plato.stanford.edu/>

pieS: Narrow your search by **source** or **document type**

Select a search tool and approach according to your needs.

Books: Your library catalog, WorldCat, Google Books

Articles: PubMed, Google Scholar, EthicShare

Websites: Google, directories and subject guides, social search tools

Legal and regulatory documents: Google Scholar, International Compilation of Human Subject Protections (OHRP), government websites

Govt. and Int. Org. publications: Science.gov, Google (advanced search), Govt/IO sites

Grey literature: Google, Scirus, The Grey Literature Report (nyam.org)

News: Google News, Yahoo News, EthicShare

Case studies: NRCBL, Ethics Education Library, Google (advanced search)

Syllabi: NRCBL, Ethics Education Library, Google (advanced search)

Organizations: NRCBL, Global Ethics Observatory, BEKIS at DRZE

Clinical trials data: ClinicalTrials.gov, ICTRP, CenterWatch

Industry reports: PhRMA, CenterWatch, Google (advanced search)

“Research is re-searching,” but ...

Ask for help when you're stuck

1. Colleagues
2. Email lists and social networks:
 - a. International-Bioethics listserv (FIC-NIH)
 - b. Globethics.net forum
 - c. EthicShare.org
3. Librarians

Know when “enough is enough”



Ethics and the Access Problem

You found it, but can you read it ... for free?

1. Here at the IU School of Medicine, we have print and digital access to a large body of ethics literature.
2. What can't be accessed today, arrives in a few days by **interlibrary loan**.
3. However, internationally, only a few people are served by large university libraries:
 - a. Some countries are served by HINARI:
<http://www.who.int/hinari/en/>
 - b. Globethics.net provides access to a free, but relatively limited collection
 - c. One may use open-access publishers and archives, but ...

How “open” is the ethics literature?



INDIANA UNIVERSITY
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Indiana University-Moi University Academic Research Ethics Partnership

TaSKR III
April 12-14, 2011
Indianapolis, Indiana

Binder Index

TaSKR III Agenda

Overview of TaSKR III

People

- List of Participants
- Speaker Photos and Biographies

Reading Materials

1. Keynote Address: Global Bioethics – between Globalization and Localization

Henk ten Have (Duchessne University)

- Chadwick R, ten Have H, Meslin EM. Health care ethics in an era of globalization. In: Chadwick R, ten Have H, Meslin EM, editors. *The SAGE Handbook of Health Care Ethics*. Los Angeles (CA): SAGE; 2011. p. 1-9.
- ten Have H, Jean MJ. Introduction. In: ten Have H, Jean MJ, editors. *The UNESCO Universal Declaration on Bioethics and Human Rights. Background, Principles and Application*. Paris: UNESCO Publishing; 2009. p. 17-55.

The screenshot shows the website for the Indiana University Center for Bioethics, specifically the "Kenya: Research Ethics Bibliography" page. The page header includes the center's name and navigation links for the Department of Medicine, IRSE, IRPE, and Contact Us. The main content area is divided into sections: HOME, ABOUT, EDUCATION, GIVE, NEWS, PEOPLE, and PROGRAMS. The EDUCATION section contains a paragraph about the development of an international research ethics bibliography for Kenya. The PEOPLE section lists several researchers and their publications, including articles on critical care in resource-poor settings, medical research in East Africa, and community engagement in Kenya. A sidebar on the right titled "International Research Ethics" contains links to the bibliography, a subject guide, and teaching skills resources.

<http://bioethics.iu.edu/kenyabibliography>



BioMed Central Blog

SUNDAY JUL 22, 2007

How open access is your research area?

Using PubMed's "Limits" tab, it is easy to filter searches by date of publication, and also by whether an article has a link to an online full text, and whether that online full text is freely available.



http://blogs.openaccesscentral.com/blogs/bmcblog/entry/how_open_access_is_your

Cost of articles in the TaSkR III binder: \$436.00

\$140.00 = Chadwick R, ten Have H, Meslin EM. Health care ethics in an era of globalisation. In: Chadwick R, ten Have H, Meslin EM, editors. *The SAGE Handbook of Health Care Ethics*. Los Angeles (CA): SAGE; 2011. p. 1-9.

\$80.00 = Benatar SR. New perspectives on international research ethics. In: Hayry M, Takala T, Herissone-Kelly P, editors. *Ethics in Biomedical Research: International Perspectives*. Amsterdam and New York: Rodopi Press; 2005. p. 9-19.

\$53.50 = Benatar SR. Towards progress in resolving dilemmas in international research ethics. *Journal of Law, Medicine and Ethics*. 2004;32(4):574-82.

\$53.50 = Steinert Y. Student perceptions of effective small group teaching. *Medical Education*. 2004;38(3):286-93.

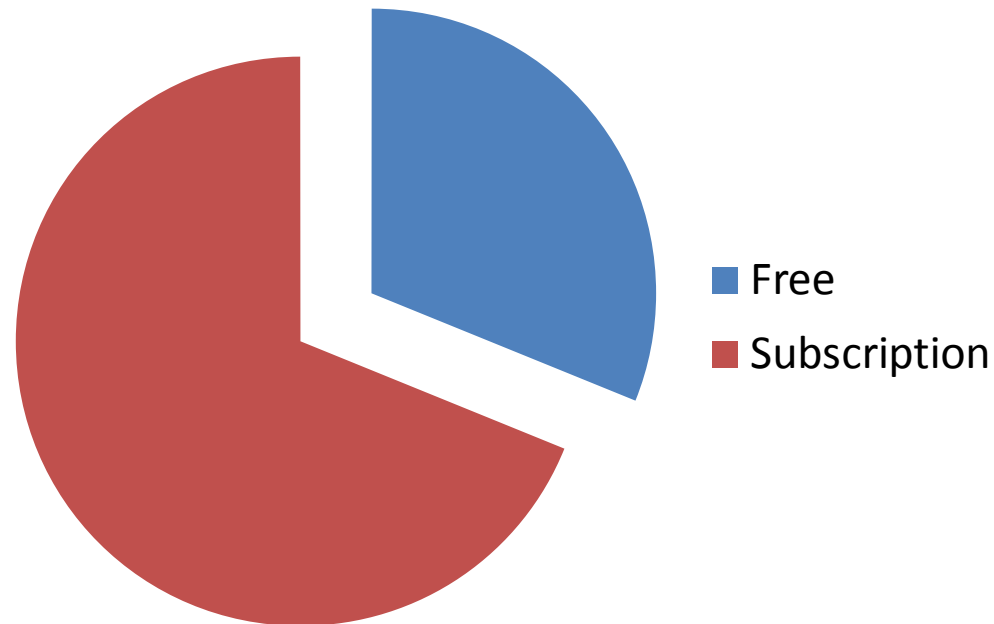
\$52.00 = ten Have H, Jean M. *The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application*. Paris: UNESCO Publishing, 2009.

\$45.00 = Benatar SR, Landman WA. Bioethics in South Africa. *Cambridge Quarterly of Healthcare Ethics*. 2006;15:239-47.

\$12.00 = Sleem H, Abdelhai RAA, Al-Abdallat I, Al-Naif M, Gabr HM, Kehil E, Sadiq BB, Yousri R, Elsayed D, Sulaiman S, Silverman H. Development of an accessible self-assessment tool for research ethics committees in developing countries. *Journal of Empirical Research on Human Research Ethics*. 2010;5(3):85-98.

Free articles in the “Kenya: Research Ethics Bibliography”

$$19/42 = .45^*$$



* Accessed on April 11, 2011 from: <http://bioethics.iu.edu/kenyabibliography>

Open Access to the Ethics Literature Indexed in PubMed Medline

60 day Open Access Quotient

Free full text / Links to full text

bioethics[sb] AND ("loattrfree full text"[sb] AND "2011/02/11"[PDat] :
"2011/04/11"[PDat])

bioethics[sb] AND ("loattrfull text"[sb] AND "2011/02/11"[PDat] :
"2011/04/11"[PDat])

Adapted from: How open access is your research area? BioMed Central Blog. July 22, 2007. Available from: http://blogs.openaccesscentral.com/blogs/bmcblog/entry/how_open_access_is_your

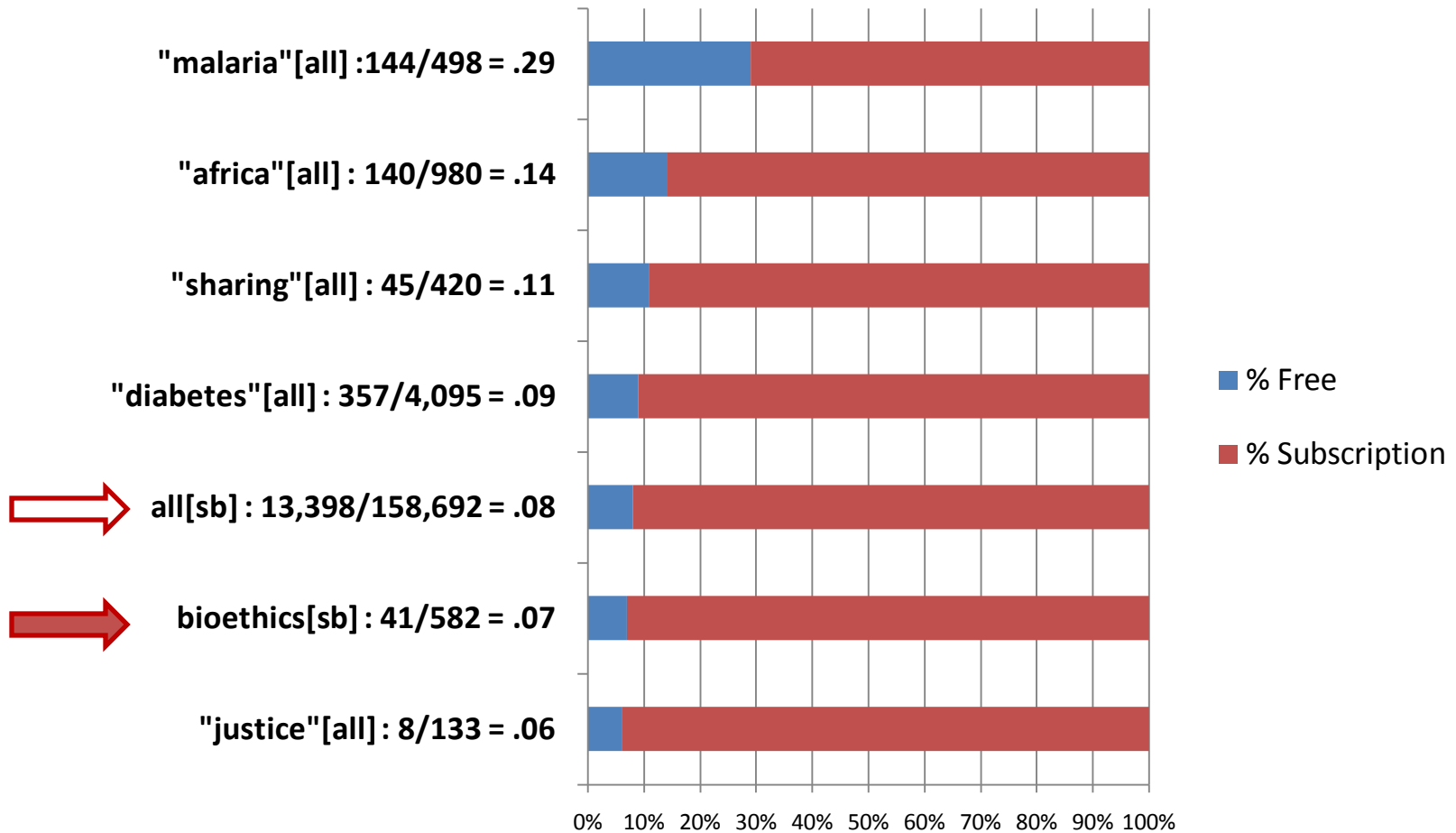
Bioethics: 93% Closed

41 free articles / 582 articles = .07

On April 11, 2011 only 7% of the recent bioethics literature was open to all readers.



Open access of bioethics compared to other subjects



What can you do about the access problem?

1. **Support** local and public efforts to encourage open-access publishing and archiving. Start by learning more about open access. Here's a brief overview by Peter Suber:
<http://www.earlham.edu/~peters/fos/brief.htm>
2. **Comply** with the NIH Public Access Policy: requires that papers resulting from NIH-funded research to be “accessible to the public on PubMed Central no later than 12 months after publication.” See:
<http://publicaccess.nih.gov/>
3. **Submit**, when possible, your papers to open-access publishers. To find an open-access journal, visit the Directory of Open Access Journals at:
<http://www.doaj.org/>
4. **Self-archive your work in a reputable digital repository**

Tips for self-archiving

1. **Ask** your publisher before and after publication about the self-archiving policy (don't be shy).
2. **Save** the late-stage versions of your article or chapter: some publishers permit authors to archive the preprint of the “final draft.”
3. **Archive** your work in an Open Archives Initiative (<http://www.openarchives.org/>) standards compliant site.

Digital archives for ethics literature

1. Most academic and disciplinary archives meet OAI standards. If you have a bioethics article, I'd love to help you add it to the **Bioethics Digital Library** (<http://bioethics.iu.edu/bedl>). Or find a place in:
 - a. **Your university's archive.**
 - b. EthicShare.org: <https://www.ethicshare.org/>
 - c. Globethics.net: <http://www.globethics.net/>
 - d. SSRN: <http://www.ssrn.com/>
 - e. PhilPapers: <http://philpapers.org/>
2. To find an Open Access Archive, visit: <http://www.opendoar.org/>
3. For a handy database of publisher's open-access policies, visit: SHERPA/RoMEO - <http://www.sherpa.ac.uk/romeo/>

The open-access archiving spectrum

(From: <http://www.sherpa.ac.uk/romeoinfo.html>)



green - can archive pre-print and post-print or publisher's version/PDF



blue - can archive post-print (ie final draft post-refereeing) or publisher's version/PDF



yellow - can archive pre-print (ie pre-refereeing)



white - archiving not formally supported

Why should you open access to your work? It's good for you!

1. **Open-access articles have a broader readership** (Davis PM. Open access, readership, citations: a randomized controlled trial of scientific journal publishing. FASEB J. 2011 Mar 30.)
2. **Open-access articles may be cited more often** (Gargouri Y, Hajjem C, Larivière V, Gingras Y, Carr L, Brody T, Harnad S. Self-selected or mandated, open access increases citation impact for higher quality research. PLoS One. 2010 Oct 18;5(10):e13636.)
3. **Open-access articles save you and your institutions subscription costs:**
[T]he cost of scholarly journals has increased at 10% per year for the last three decades. This is over six times the rate of general inflation and over two and a half times the rate of increase of the cost of health care.

David W. Lewis. Library budgets, open access, and the future of scholarly communication. C&RL News. May 2008. p. 271-3. Available from:

<http://crln.acrl.org/content/69/5/271.full.pdf>

Unlock access to your work: it's good for everyone!

1. HINARI provides only limited access
2. Public access mandates often include lengthy embargos
3. Do your part to open the science for all



More information ...

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IUCB Bioethics Reference Center - <http://bioethics.iu.edu/reference-center/>

International Research Ethics subject guide – <http://bioethics.iu.edu/ireguide>

Kenya: Research Ethics Bibliography – <http://bioethics.iu.edu/kenyabibliography>

Finding Bioethics Information – <http://bioethics.iu.edu/finding>

Demo? / Questions?

The screenshot shows the PubMed website. At the top, there is a navigation bar with the NLM logo and the text "PubMed.gov". Below this is a search bar with a dropdown menu set to "PubMed" and buttons for "Search" and "Clear". A main banner features the PubMed logo and a description: "PubMed comprises more than 20 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher web sites." Below the banner are three columns of links: "Using PubMed" (PubMed Search, PubMed Central, Full Text Articles, PubMed Links, PubMed Subsites, News and Announcements), "PubMed Tools" (PubMed Home, Search Citation Matcher, Batch Citation Matcher, Clinical Queries, Data Search Service), and "More Resources" (Web Databases, Journals in NLM Databases, Clinical Trials).

The screenshot shows the Google Scholar beta search page. It features the Google Scholar logo in the center. Below the logo is a search input field with a "Search" button and a link to "Advanced Search". At the bottom, there are checkboxes for "Articles (T* include patents)" and "Legal opinions and journals".

The screenshot shows the WorldCat website. The main heading is "Find items in libraries near you" with a subtext "1.5 billion items available here through a library". Below this is a search bar with a dropdown menu set to "Everything" and buttons for "Books", "Articles", "E-books", and "Articles". A search input field is followed by a "Search everything" button. To the right, there is a sign-up section titled "Sign up to create lists, bibliographies and access to library materials" with fields for "First Name" and "Password", a checkbox for "Remember me on this computer", and buttons for "Continue" and "Create your account!". At the bottom, there are two promotional banners: "New for WorldCat.org: New iPhone app with WorldCat results" and "Expert Search indexes now available".