Finding what you need?
Information resources for international research ethics

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Teaching Skills in International Research Ethics (TaSkR) III
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Bioethics Reference Center

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

- a small, non-circulating print collection (~1,000 volumes)

- a growing digital collection

- online information tools

- in-depth reference support

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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://iucat.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?

http://bioethics.iu.edu/kenyabibliography

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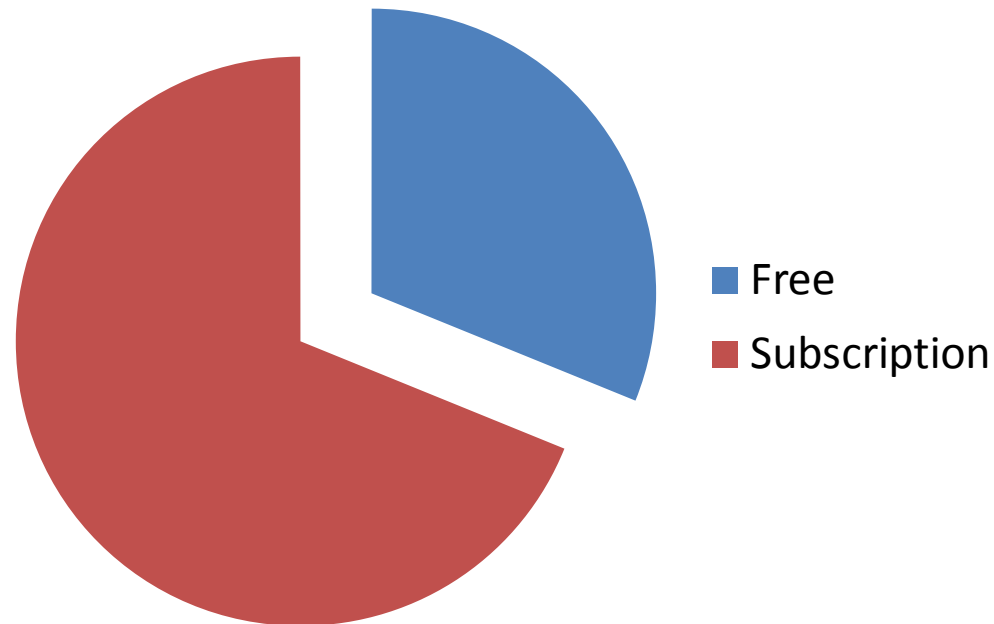
$52.00 = ten Have H, Jean M. *The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application*. Paris: UNESCO Publishing, 2009.

$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*

Free

Subscription

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])

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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
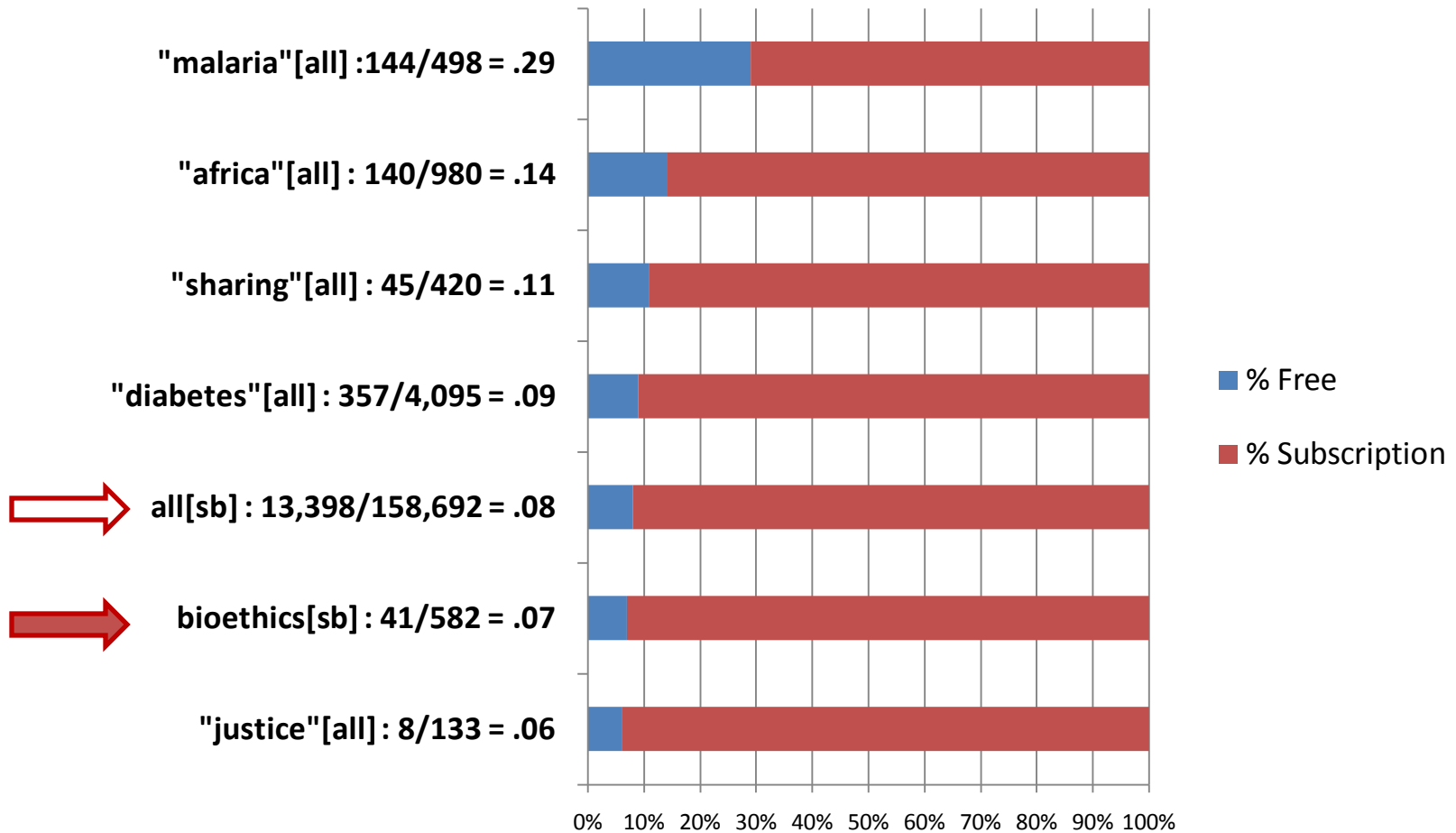
Bioethics: 93% Closed

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 be 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?