

University of Kentucky
School of Information Science (SIS)

LIS627 201 Consumer Health Information Resources
Spring 2020

Instructor

Jeff Huber
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Office Hours

- By Appointment

Class Information

- Online

COURSE INFORMATION

Course Description

History and development of consumer health information resources; role of professional and governmental agencies in provision of consumer health information; policy issues related to provision of consumer health information. Consumer health professional literature, user information needs, user resources, and information services. Identification, selection, utilization, and evaluation of consumer health information for special populations within specialized educational and healthcare settings. Trends and issues in consumer health informatics.

Course Objectives

This course is designed to provide an overview of consumer health information resources for use in public, educational, and healthcare settings.

Upon successful completion of this course, the student will:

- 1) Understand the historical origins of consumerism and the use of consumer health information including implications of consumerism within the managed care environment as well as digital environments (Assignment #1);
- 2) Understand the differences in responsibilities between consumer health librarians and other librarians as well as current trends and issues in consumer health librarianship (Assignment #3, #6, #7);
- 3) Recognize the role of regional, national, and international agencies in the provision of consumer health information. Includes professional and government

organizations, policy-making bodies, and cooperative efforts for consumer education and health promotion and research (Virtual Guests' Discussion Boards, Assignment #6, #7);

- 4) Identify, select, use, and evaluate print, multimedia, and electronic resources for consumer health information (Assignment #2, #4, #5);
- 5) Identify, select, use, and evaluate health information resources for special populations and environments including; alternative and complementary therapies, resources for chronic disease, gender and age-related tools, resources for caregivers, and health information for minority and ethnic groups (Assignment #2, #4, #5), and;
- 6) Explore trends in consumer health informatics related to user education, knowledge management, and research and development (Assignment #2, #6, #7).

Course Overview

This course is taught in distance education format. The majority of the course is conducted via Canvas. It is expected that students will devote a considerable amount of time outside the formal class to study materials covered as well as become acquainted with the literature and reference tools.

There will be a series of assignments distributed throughout the course of the semester. These assignments are based on information and resources covered in the class and readings. These assignments comprise the majority of the student's grade. Completed assignments are expected to be returned to the instructor prior to or on the date noted on the assignment. Late assignments will only be accepted with prior permission from the instructor.

Late Assignments:

Assignments should be turned in on or before the day specified. For each week an assignment is late, 10% of the grade will be subtracted. Late assignments will only be accepted with prior permission from the instructor.

Incompletes:

A grade of Incomplete due to illness or other emergencies may be arranged. A request for an Incomplete due to illness must be accompanied by a letter from your doctor, the Student Health Service, or a hospital. Lack of time to complete assigned work, or other reasons not related to unavoidable excused reasons, will not be accepted.

Academic Integrity:

All papers and assignments must represent the student's original work. When using material from other sources, proper citations must be given. Papers or assignments prepared for other classes cannot be used to fulfill the requirements of this class. See the UK Code of Student Conduct for more on academic integrity.

Required Reading

Required Readings:

Select journal articles and web sites are indicated for each week in the Course Calendar section of the syllabus.

Suggested Text (not required):

Spatz M (ed.) The Medical Library Association Guide to Providing Consumer and Patient Health Information. Lanham, MD : Rowan & Littlefield, 2014.

Supplemental Materials:

Handouts will be distributed throughout the course of the semester.

Consumer Health Resources (National Network of Libraries of Medicine, National Library of Medicine)

Available at:

<https://nnlm.gov/pnr/guides/training-resources-you-can-use/consumer-health-resources>

STUDENT EVALUATION

Grading Parameters

There will be a series of 7 assignments for the course (including a term paper and a summary reflection paper):

- Assignment 1 – Historical Paper
- Assignment 2 – Consumer Health Educational Opportunity
- Assignment 3 – Interview
- Assignment 4 – Consumer Evaluation Guide
- Assignment 5 – Annotated Bibliography
- Assignment 6 – Term Paper
- Assignment 7 – Reflection Paper

Student Evaluation:

<u>Assignments</u>	<u>Points</u>
Class participation	5
Assignment #1 – Historical Paper	10
Assignment #2 – Consumer Health Educational Opportunity	20
Assignment #3 – Interview	15
Assignment #4 – Consumer Evaluation Guide	10
Assignment #5 – Annotated Bibliography	15
Assignment # 6 - Term paper	20
Assignment #7 – Reflection paper	5
Total	100

Grading Policy:

Class assignments are due on or by the due date noted on the individual assignments. The majority of the student's grade is based on the cumulative total received on individual assignments. Late assignments will only be accepted with prior approval from the instructor.

Grading Scale

- 90% – 100% = **A (Exceptional Achievement)**
- 80% – 89% = **B (High Achievement)**
- 70% – 79% = **C (Average Achievement)**
- 0% – 69% = **E (Failing)**

Participation

Students are expected to participate in class discussion via the Discussion Boards.

There will be a series of guest experts during the course of the semester. Each will post an introduction that includes information about their current position or work

environment. Students are expected to be prepared to pose questions to our guest experts and generate discussion.

Submission of Course Assignments

Assignment should be submitted via e-mail as Word attachments or posted in the Grades section of the Canvas course shell.

Class assignments are due on or by the due date noted on the individual assignments. The majority of the student's grade is based on the cumulative total received on individual assignments. Late assignments will only be accepted with prior approval from the instructor.

TECHNOLOGY INFORMATION & RESOURCES

Distance Learning Students are expected to have a minimum level of technological acumen and the availability of technological resources. Students must have regular access a computer with a reliable Internet connection and audio capabilities. Internet Explorer 7 (IE) or Firefox 2.x are the recommended browsers for those using a Windows-based PC. Those using Firefox 3.x may encounter problems with assignment uploads. Those using an Apple computer with MAC OS X (10.5.x) may use Firefox 3.x or Safari 3.x.

Please be certain that your computer and/or browser allow you to view Adobe Reader documents (.pdf). Microsoft Office and other software products are free for students: <https://www.uky.edu/its/customer-support-student-it-enablement/customer-services/software-downloads>.

As your instructor, I am your first go-to person for technology problems. If you need more immediate assistance, please contact TASC or UKIT.

Library Services

Distance Learning Services

<http://www.uky.edu/Libraries/DLLS>

- Carla Cantagallo, DL Librarian
- Local phone number: 859 257-0500, ext. 2171; long-distance phone number: (800) 828-0439 (option #6)
- Email: dllservice@email.uky.edu
- DL Interlibrary Loan Service:
http://www.uky.edu/Libraries/libpage.php?lweb_id=253&lib_id=16

GENERAL COURSE POLICIES

Policies concerning academic integrity, excused absences and academic accommodations due to disability are available online at:

<https://ci.uky.edu/sis/sites/default/files/policies.pdf>

COURSE CALENDAR

Course Calendar:

January 16

Introduction.

Overview of the course.

Course outline, assignments, exercises, and expectations.

Text and supplemental materials.

Consumerism and the health care environment: historical overview and current trends and issues.

Consumer health information (CHI) overview.

READING: Huber JT, Gillaspay ML. Knowledge/Power Transforming the Social Landscape: The Case of the Consumer Health Information Movement. *Library Quarterly*. 81(4), October 2011, 405-430. Available via Academic Search Complete database.

Bess D. Consumer Health Education. *Proceedings of the Academy of Political Science*. 32(3), Health Services: The Local Perspective (1977), 182-192. Available via JSTOR database.

Duval MK, Den Boer J. Consumer Health Education. *Proceedings of the Academy of Political Science*. 33(4), Regulating Health Care: The Struggle for Control (1980), 168-181. Available via JSTOR database.

ASSIGNMENT #1 DISTRIBUTED, DUE JANUARY 30.

January 23

Collection development

General health books, clearinghouses, and resources

READING: Gillaspay ML and Pranic MO. Consumer Health Sources. In: Introduction to Reference Sources in the Health Sciences. Compiled and Edited by Jeffrey T. Huber and Susan Swogger. 6th edition. New York: Medical Library Association/Neal-Schuman Publishers, 2014.

ASSIGNMENT #2 DISTRIBUTED, DUE MARCH 5.

January 30

Assignment #1 due.

Electronic CHI resources

READING: Zhang Y, Sun Y, Xie Bo. Quality of Health Information for Consumers on the Web: A Systematic Review of Indicators, Criteria, Tools, and Evaluation Results. *Journal of The Association for Information Science and Technology*. 66(10), 2015, 2071-2084.
Available via Academic Search Complete database.

Deardorff A, Masterson K, Roberts K, Killicoglu H, Demner-Fushman D. A Protocol-Driven Approach to Automatically Finding Authoritative Answers to Consumer Health Questions in Online Resources. *Journal of The Association for Information Science and Technology*. 68(7), 2017, 1724-1736.
Available via Academic Search Complete database.

Zhang Y. Beyond Quality and Accessibility: Source Selection in Consumer Health Information Seeking. *Journal of The Association for Information Science and Technology*. 65(5), 2014, 911-927.
Available via Academic Search Complete database.

Lee K, Hoti K, Hughes JD, Emmerton LM. Interventions to Assist Health Consumer to Find Reliable Online Health Information: A Comprehensive Review. *PLOS ONE*. 9(4), (April 2014), e94186.
Available via PLOS ONE: www.plosone.org

SUPPLEMENTAL READING:

Kovacs DK. Why Develop Web-Based Health Information Workshops for Consumers? *Library Trends*. 53(2), (Fall 2004), 348-359.
Available via Academic Search Complete database.

Crespo J. Training the Health Information Seeker: Quality Issues in Health Information Web Sites. *Library Trends*. 53(2), (Fall 2004), 360-374.
Available via Academic Search Complete database.

Miller N, Tyler RJ, Backus JEB. MedlinePlus: The National Library of Medicine Brings Quality Information to Health Consumers. *Library Trends*. 53(2), (Fall 2004), 375-388.
Available via Academic Search Complete database.

Marill J, Miller N, Kitendau P. The MedlinePlus Public User Interface: Studies of Design Challenged and Opportunities. *Journal of the Medical Library Association*. 94(1), (Jan 2006), 30-40.
Available via Academic Search Complete database.

ASSIGNMENT #6 TERM PAPER ASSIGNMENT DISTRIBUTED, DUE APRIL 23.

ASSIGNMENT #3 DISTRIBUTED, DUE FEBRUARY 27.

February 6

Book reviews

Review relevant web sites:

Doody's Review Service

<http://www.doody.com/drs/>

February 13

Pamphlets

GUEST EXPERT: Derek Johnson, Health Professionals Outreach, and Sam Watson, Outreach Specialist, Greater Midwest Region, National Networks of Libraries of Medicine, National Library of Medicine, University of Iowa, Iowa City, IA.

February 20

Provision of CHI resources and services.

Professional organizations

Government agencies/entities

Review relevant web sites:

National Library of Medicine

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

National Network of Libraries of Medicine, National Library of Medicine

<http://nmlm.gov/>

National Health Information Center

<http://www.health.gov/nhic/>

Medical Library Association

<http://www.mlanet.org>

Medical Library Association Consumer Health Information Specialization Program

<http://www.mlanet.org/p/cm/ld/fid=329>

Consumer and Patient Health Information Section (CAPHIS), Medical Library Association

<https://www.mlanet.org/caphis>

February 27

Assignment #3 due.

Diverse user populations

READING: Seeleman C, Esskink-Bot ML, Stronks K, Ingleby D. How Should Health Service Organizations Respond to Diversity? A Content Analysis of Six Approaches. *BMC Health Services Research*. 15, 16 November 2015, 510.

Available via Academic Search Complete database.

Alpi KM, Bibel BM. Meeting the Health Information Needs of Diverse Populations. *Library Trends*. 53(2), (Fall 2004), 268-282.

Available via Academic Search Complete database.

Detlefsen EG. Where Am I to Go? Use of the Internet for Consumer Health Information by Two Vulnerable Communities. *Library Trends*. 53(2), (Fall 2004), 283-300.

Available via Academic Search Complete database.

Allen M, Matthew S, Boland MJ. Working with Immigrant and Refugee Populations: Issues and Hmong Case Study. *Library Trends*. 53(2), (Fall 2004), 301-328.

Available via Academic Search Complete database.

Chu A, Huber J, Mastel-Smith B, Cesario S. "Partnering with Senior for Better Health": Computer Use and Internet Health Information Retrieval Among Older Adults in a Low Socioeconomic Community. *Journal of the Medical Library Association*. 97(1), (January 2009), 12-20.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/pubmed>

March 5

Assignment #2 due.

Health literacy

GUEST EXPERT: Robert M. Shapiro II, Public Health Librarian, Academic Liaison for the College of Public Health, Medical Center Library, University of Kentucky, Lexington, KY

Review relevant web sites:

Consumer Health Information in Many Languages
Resources

<https://nmlm.gov/consumer-health-information-many-languages-resources>

READING: Huber JT, Shapiro II RM, Gillaspay ML. Top Down Versus Bottom Up: The Social Construction of the Health Literacy Movement. *Library Quarterly*. 82(4), (Oct. 2012), 429-451.
Available via Academic Search Complete database.

Noh Y. The Development and Performance Measurements of Educational Programs to Improve Consumer Health Literacy. *Reference & User Services Quarterly*. 53(2), (Winter 2013), 140-154.

Buchter RB, Fechtelpeter D, Knelangen M, Ehrlich M, Watering A. Words or Numbers? Communicating Risk of Adverse Effects in Written Consumer Health Information: A Systematic Review and Meta-Analysis. *BMC Medical Informatics and Decision Making*. 14:76, (26 August 2014).
Available via BioMedCentral: <https://www.biomedcentral.com/>

SUPPLEMENTAL READING:

Sandstrom HT. Watch Your Language. *Library Trends*. 53(2), (Fall 2004), 329-335.
Available via Academic Search Complete database.

Baker LM, Gollop CJ. Medical Textbooks: Can Lay People Read and Understand Them? *Library Trends*. 53(2), (Fall 2004), 336-347.
Available via Academic Search Complete database.

Burnham E, Peterson EB. Health Information Literacy: A Library Case Study. *Library Trends*. 53(3), (Winter 2005), 422-433.
Available via Academic Search Complete database.

Parker R, Kreps GL. Library Outreach: Overcoming Health Literacy Challenges. *Journal of the Medical Library Association*. 93(4 Suppl), (Oct 2005), S81-S85.
Available via Academic Search Complete database.

SUGGESTED READING:

Health Literacy: A Prescription to End Confusion. Editors Lynn Nielsen-Bohlman... [et al]; Committee on Health Literacy, Board on Neuroscience and Behavioral Health, Institute of Medicine. Washington, DC: The National Academic Press, 2004.

March 12

Outreach and advocacy

READING: Huber JT, Kean EB, Fitzgerald PD, Altman TA, Young ZG, Dupin KM, Leskovec J, Holst R. Outreach Impact Study: The Case of the Greater Midwest Region. *Journal of the Medical Library Association*. 99(4), (October 2011), 297-303.

Available via PubMed Central at <http://www.ncbi.nlm.nih.gov/pmc/>

Ruffin AB, Cogdill K, Kutty L, Hudson-Ochillo M. Access to Electronic Health Information for the Public: Analysis of Fifty-Three Funded Projects. *Library Trends*. 53(3), (Winter 2005), 434-452.
Available via Academic Search Complete database.

Press NO, Diggs-Hobson M. Providing Health Information to Community Members Where They Are: Characteristics of the Culturally Competent Librarian. *Library Trends*. 53(3), (Winter 2005), 397-410.
Available via Academic Search Complete database.

Spatz MA. Building Community Bridges for Health: Consumer Health Librarians as Health Advocates. *Library Trends*. 53(3), (Winter 2005), 453-456.
Available via Academic Search Premier database.

Kenyon A. Philly Health Info: The College of Physicians of Philadelphia's Regional Community Health Information Project. *Library Trends*. 53(3), (Winter 2005), 457-463.
Available via Academic Search Complete database.

March 19

NO CLASS – SPRING BREAK

March 26

Public libraries as CHI resources

GUEST EXPERT: Kay Hogan Smith, Professor/Senior Research Librarian & Liaison to the School of Public Health, UAB Lister Hill Library of the Health Sciences, University of Alabama at Birmingham, Birmingham, AL

READING: Kouame G, Harris M, Murray S. Consumer Health Information from Both Sides of the Reference Desk. *Library Trends*. 53(3), (Winter 2005), 464-479.
Available via Academic Search Premier database.

Gillaspy M. Factors Affecting the Provision of Consumer Health Information in Public Libraries: The Last Five Years. *Library Trends*. 53(3), (Winter 2005), 480-495.
Available via Academic Search Complete database.

Smith C, Logsdon K, Clark M. Consumer Health Information Services at Iowa City Public Library. *Library Trends*. 53(3), (Winter 2005), 496-511.
Available via Academic Search Complete database.

Wood FB, Lyon B, Schell MB, Kitendaugh P, Cid VH, Siegel ER. Public Library Consumer Health Information Pilot Project: Results of a National Library of Medicine Evaluation. *Bulletin of the Medical Library Association*. 88(4), (October 2000), 314-322.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

The Challenge of Providing Consumer Health Information Services in Public Libraries. American Association for the Advancement of Science. Available at:

<http://ehrweb.aaas.org/PDF/ChallengePubLibraries.pdf>

ASSIGNMENT #4 DISTRIBUTED, DUE April 2

April 2

Assignment #4 due

Patient Bill(s) of Rights

Ethical issues and considerations

Review examples of Patient Bill(s) of Rights:

The Patient Care Partnership (American Hospital Association)

<http://www.aha.org/aha/issues/Communicating-With-Patients/pt-care-partnership.html>

The Patient's Bill of Rights (American Cancer Society)

http://www.cancer.org/docroot/MIT/content/MIT_3_2_Patients_Bill_Of_Rights.asp

The Patient's Bill of Rights in Medicare and Medicaid (US Department of Health and Human Services)

<http://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Market-Reforms/Patients-Bill-of-Rights.html>

Health Insurance Portability and Accountability Act of 1996 (HIPAA)

Your Rights Under HIPAA

<https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html>

READING: Carbo T. Challenges for Libraries Creating One World: Information Ethics and Policy Issues for Medical Librarians. *Journal of the Medical Library Association*. 91(3), (July 2003), 281-284.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

Rothstein JA. Ethics and the Role of the Medical Librarian: Health Care Information and the New Consumer. *Bulletin of the Medical Library Association*. 81(3), (July 1993), 253-258.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

Dyer DA. Ethical Challenges of Medicine and Health on the Internet: A Review. 3(2), (2001), e23.

Available at:

<http://www.jmir.org/2001/2/e23/>

ASSIGNMENT #5 DISTRIBUTED, DUE APRIL 16

April 9

e-Health

Consumer health informatics

Review relevant web sites:

Organized Wisdom

<http://www.organizedwisdom.com>

PatientsLikeMe

<http://www.patientslikeme.com>

Everyday Health

<http://www.everydayhealth.com>

READING: Free C, Phillips G, Galli L, Watson L, Felix L, Edwards P, Patel V, Haines A. The Effectiveness of Mobile-Health Technology-Based Health Behavior Change or Disease Management Interventions for Health Care Consumers: A Systematic Review. PLOS Medicine. 10(1), (January 2013), e1001362.

Available via PLOS Medicine: www.plosmedicine.org

Flaherty D, Hoffman-Goetz L, Arocha J. What is Consumer Health Informatics? A Systematic Review of Published Definitions. Informatics for Health and Social Care. 40(2), 2015, 91-112.

Available via Academic Search Complete database.

Zhao Y, Zhang J. Consumer Health Information Seeking in Social Media: A Literature Review. Health Information & Libraries Journal. 34, 2017, 268-283.

Available via Academic Search Complete database.

Goldberg L, Lide B, Lowry S, Massett HA, O'Connell T, Preece J, Quesenberry W, Shneiderman B. Usability and Accessibility in Consumer Health Informatics: Current Trends and Future Challenges. American Journal of Preventive Medicine. 40(5S2), 2011, S187-S197.

Available via Academic Search Complete database.

SUPPLEMENTAL READING:

Eysenbach G. What is e-Health? Journal of Medical Internet Research. 3(2), (2001), e20

Available at:

<http://www.jmir.org/2001/2/e20/>

Eysenbach G, Jadad AR. Evidence-Based Patient Choice and Consumer Health Informatics in the Internet Age. Journal of Medical Internet Research. 3(2), (2001), e19.

Available at:

<http://www.jmir.org/2001/2/e19/>

Eysenbach G, Powell J, Rizo C, Stern A. Health Related Virtual Communities and Electronic Support Groups. BMJ. 328(7449), (May 15 2004), 1166.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

April 16

Assignment #5 due

Complementary and alternative medicine

Review relevant web sites:

National Center for Complementary and Integrative Health

<https://nccih.nih.gov/>

READING: Crawford GA. Complementary and Alternative Medicine. Reference & User Services Quarterly. 42(4), (Summer 2003), 296-306.

Available from Library Literature and Information Science Full Text database.

Crumley ET. Exploring the Roles of Librarians and Health Care Professionals Involved with Complementary and Alternative Medicine. Journal of the Medical Library Association. 94(1), (January 2006), 81-9.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

Nims JK. Complementary and Alternative Medicine. An Overview of Nontraditional Medicine on the Web. College & Research Libraries News. 63(8), (S 2002), 576-579, 589, 599.

Available via Library Literature and Information Science Full Text database.

April 23

Term paper due.

Information seeking and use.

Evaluation.

READING: Dervin B. Libraries Reaching Out with Health Information to Vulnerable Populations: Guidance from Research on Information Seeking and Use. Journal of the Medical Library Association. 93(4 Suppl), (Oct 2005), S74-S80.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

Olney CA. Using Evaluation to Adapt Health Information Outreach to the Complex Environments of Community-Based Organizations. Journal of the Medical Library Association. 93(4 Suppl), (Oct 2005), S57-S67.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

Ottoson JM, Green LW. Community Outreach: From Measuring the Difference to Making a Difference with Health Information. Journal of the Medical Library Association. 93(4 Suppl), (Oct 2005), S49-S56.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

SUGGESTED READING:

Burroughs, Catherine M. and Fred B. Wood. Measuring the Difference: Guide to Planning and Evaluating Health Information Outreach. Seattle, Washington: National Network of Libraries of Medicine, Pacific Northwest Region; Bethesda, MD: National Library of Medicine, 2000.

Available at:

<https://nmlm.gov/neo/professional-development/guides>

ASSIGNMENT #7 REFLECTION PAPER ASSIGNMENT DISTRIBUTED, DUE APRIL 30.

April 30

Reflection paper due.

Future directions.

Student evaluations of course.

READING: Shen B. Ecologies, Outreach, and the Evolution of Medical Libraries. Journal of the Medical Library Association. 93(4 Suppl), (Oct 2005), S86-S92.

Available via PubMed at:

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

COURSE ASSIGNMENTS

<u>Assignments</u>	<u>Points</u>
Class participation	5
Assignment #1 – Historical Paper	10
Assignment #2 – Consumer Health Educational Opportunity	20
Assignment #3 – Interview	15
Assignment #4 – Consumer Evaluation Guide	10
Assignment #5 – Annotated Bibliography	15
Assignment # 6 - Term paper	20
Assignment #7 – Reflection paper	5
Total	100