

Information Retrieval to Support Research in Health Studies

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REVISED VERSION Dec. 11, 2007

Abstract

The breadth and interdisciplinary nature of health studies makes information gathering complex. The “ask, acquire, appraise, apply” approach is described as a strategic framework for researching health studies questions in the existing literature. Interwoven into a discussion of the four stage strategy is an overview of some of the major social, political, ethical, and economic issues that affect health information production, publication, accessibility, and quality.

Researchers must begin by framing an answerable question with appropriate vocabulary.

Acquiring appropriate and relevant information typically requires searching multiple databases and other sources. The reader must take responsibility for the ultimate critical appraisal of the information gathered due to the limitations and biases inherent in the publication process.

Barriers to the availability, accessibility, and reliability of information include publication bias, cost, gaps in the research literature, conflict-of-interest, cultural, geographic, and ideological biases.

The “evidence based” paradigm is briefly described as an example of an approach for applying information research in health practice. Though not intended as a guide to specific information resources, examples of major health information sources are provided to illustrate concepts.

I. A strategy for seeking health information

There is no agreed upon definition of “health studies”. The term tends to be used in a broad way to encompass any area of work, research and study in the social sciences, humanities, or natural sciences which focuses on human health. This can involve interdisciplinary work drawing from a wide array of disciplines, including psychology, sociology, economics, political science, management, biology, anthropology, neuroscience, women’s studies, history, philosophy, religion, statistics, and epidemiology. People engaged in health studies are employed in all spheres of society including clinical practice, social work, academia, research institutes, health systems management, public health, etc. The broad use of the term “health studies” opens up

large areas for potential study, but also creates the challenge of focusing ones research efforts effectively. The "ask-acquire-appraise-apply" approach can help provide a useful framework for structuring and conducting an information search.

This structured approach to conducting and teaching health information research arose out of the evidence-based medicine paradigm pioneered by David Sackett and his colleagues at McMaster University. The first step involves asking a specific, answerable question. Next, an information search is conducted to acquire information. The information gathered is then critically appraised for relevance, quality, and appropriateness to one's purpose. Finally, the information is analyzed and applied to the purpose. The entire process is an iterative one, as at any point in the process additional questions may arise, additional information may need to be acquired, and results of the application may require re-appraisal of the information initially obtained. For a clinical health care practitioner, where the information is used to guide an intervention with a patient or population, the additional step of assessing outcomes should also be conducted. The success or impact of the intervention is measured and the results guide clinical work, are added to the practitioner's knowledge base, and may even be published to add to the general body of knowledge. In the case of a disappointing result, all or part of the ask-acquire-appraise-apply process can be repeated to identify alternative approaches. (Sackett, 2000)

II. Ask

When asking a question, it is important to consider whether or not it is reasonably "answerable". If a question is framed too broadly, it will be impractical to gather information to address it. For example, it is not practical to approach the broad, vague question "I want information on diabetes" without some clarification of what information is being sought. On the other hand, a question can be so narrow that it is not realistic that an answer can be found. For example, it may be very difficult to find much existing, published information on the current prevalence of pre-diabetes in the population of a particular city in a small, developing country, although this question might lend itself to an original research study. It would be reasonable to research the question "What are the barriers to effective diabetes management in Africa." This

latter question specifies the aspect of diabetes that is of interest (barriers to effective management) as well as the population of interest (Africans) without being overly narrow or excessively broad. It can be helpful to do some initial background reading on a topic to get a feel for what has already been studied and therefore what questions might reasonably be answered by the existing published literature.

Vocabulary issues are also important to consider when searching for information. Different disciplines and databases often use different words to describe the same concept. To an anthropologist “culture” refers to the customs, language, and traditions of a group of people; but to a microbiologist, “culture” means growing biological materials in the laboratory. Terms used for the same concept can also change over time (e.g., Negro, Black, African American). Acronyms can be ambiguous. “SARS” can mean “severe acute respiratory syndrome” to an infectious disease specialist, but a chemist may use it to refer to “structure-activity relationships”. These considerations are important, because online systems typically only make a letter-by-letter match of what has been typed in, and are not capable of interpreting the *meaning* of the words. Some online search systems have sophisticated subject indexing and vocabulary mapping schemes (e.g., PubMed’s MeSH system) which attempt to control for vocabulary differences. Other systems simply rely on words provided by the author in the title, abstract, and keywords portions of the record (e.g. Web of Science). Also consider synonyms and closely related terms which might be necessary for an accurate or complete search. For example, malaria is a disease caused by a protozoan and transmitted by the anopheles mosquito. Depending on what you want to know, relevant articles might focus on the disease, the protozoa, the mosquito, or all three. A helpful technique is to generate a list of synonyms and related terms for each concept in your question. As you conduct your research, make note of any additional relevant terms you encounter to further enrich and expand your search.

III. Acquire

Once the question has been articulated, the next step in the information research process is acquiring information relevant to the question. The sources consulted and the information

acquired will depend on the purpose of the information quest. Examples of health information include: scholarly articles for writing a research paper on a health related topic; population based information, data and statistics to support research in sociology, anthropology or public health; information for making informed decisions as a healthcare consumer; patient education material for a healthcare provider to use in practice; scientific information for clinical research; clinical information to support patient care; and information to support healthcare policy decision making.

Secondary sources such as books, literature review articles, and reference works can provide helpful background information on a topic and can provide summary and analysis of a large amount of information. This is particularly helpful for topics on which there has been a large amount written. A literature review involves an examination and summation of an extensive amount of published research on a specific topic. While they vary in their extent, it is not unusual for a scientific literature review to survey 100 or more articles. One disadvantage of the secondary literature is that it takes a great deal of time to produce, and thus might not contain the most up-to-date information. It can take one or more years to get a book published; science and medical textbooks often go three to five years between new editions. The lag in textbooks in rapidly growing fields such as neuroscience is estimated to be 5 years, making them inadequate for even undergraduate use without supplementary information from more current sources (Cleland, 2002). Secondary literature also is limited by the perspective and biases of the authors and editors doing the synthesis. For example, a study of 50 textbooks in various medical specialties found that all were lacking in information to support end-of-life care, even when discussing terminal diseases (Rabow, 2000). For these reasons, researchers should not rely on secondary sources alone.

Primary literature includes original research articles, ethnographies, and data/statistical sources. These can provide more up-to-date information. They are often highly focused on a narrow topic of study. This limited scope is both a strength and a weakness. Primary literature provides a high level of specificity, but does not provide the broader perspective of the secondary literature. This weakness can be ameliorated by gathering multiple primary sources on a topic. In the case of a widely studied topic, a search of the recent primary research can be used to

supplement and update an existing literature review or other secondary sources on a topic. Like secondary sources, primary sources may be limited by the biases of the author.

Primary and secondary sources are typically identified by searching general and specialized databases. No single database exists which can provide all the information needed for the health studies researcher. The interdisciplinary nature of health studies necessitates use of a broad array of information sources. Think about the question posed and the types of researchers or organizations that would study the issue. Any scholarly or in-depth research on a health information topic will require consulting multiple databases or other sources. A single research project may involve gathering information from sources as diverse as the clinical medical literature, the social sciences literature, government agencies, non-governmental agencies and privately funded research foundations. Because of the often specialized nature of health information research, it is often helpful to consult with a librarian to save time and to identify sources that might otherwise be missed. A librarian can also provide access to the subscription databases that are available locally. A highly selective list to illustrate the range of health information sources is provided in Table 1.

Finding numerical data and statistics can be particularly difficult. Statistics take time to gather and compile, so the latest ones available may be less current than you'd like. Also, they may not have been gathered for the specific geographic area or population you want. For example, you may want to know the number of teenage boys in Cumberland County, Pennsylvania who ride in cars without wearing seat belts. But you may have to settle for the number of male drivers of any age in the state of Pennsylvania who responded on a self-selected survey that they sometimes do not wear a seat belt. In some cases raw data sets may be available that allow you to form a specific query and tailor the results. These data sets are being made more readily available via the world wide web. An example is the Centers for Disease Control's Wide-ranging OnLine Data for Epidemiologic Research (WONDER) system (<http://wonder.cdc.gov/>). Some systems require a subscription or purchase of the data, are restricted to certain researchers, and/or require specialized analytical software such as SPSS (for example, the Inter-University Center for Political and Social Research).

Even assuming a piece of data or statistic exists, it can be difficult to determine where to find it. It often helps to consider who might have gathered the information. For example, if you were looking for health statistics specific to one of the United States, the state department of public health website would be a logical place to start. If you were looking for statistics related to a particular country, an agency of the country's government may exist to track that data. For global health statistics, the World Health Organization would be a logical place to start. The (U.S.) National Center for Health Statistics (<http://www.cdc.gov/nchs/>) makes available a great deal of information, but is still not comprehensive for all health statistics. Statistical studies about specific topics are also published as journal articles, so searching for these using databases can be an effective strategy. The Michigan Informatics project (<http://www.sph.umich.edu/mi-info/03-hs/index.html>) has an excellent online tutorial on finding health statistics (University of Michigan, 2007).

Statistics are not the only health information that can be difficult to find. One of the biggest challenges in conducting health information research is the lack of relevant information. There are a variety of reasons why this might be the case. Sometimes a particular topic or population has simply not been studied, or has not been studied recently. Clinical studies can be difficult to design and expensive to conduct, so a relevant well-designed, large scale study may not have been conducted. Or a smaller study may not have been replicated, limiting the amount of information available. There are also many gaps in the research done among certain population groups such as women and minorities.

If you are having difficulty finding information on a particular topic, a consultation with a librarian and with experts in the particular field of interest can lead to suggestions for additional sources and search strategies. They may be able to suggest specialized databases of information or agencies that can provide relevant information. If, the information sought is simply not available, and you are not prepared to conduct an original research study, then you should consider circling back to the "ask" step and modifying the research question. Sometimes simply adjusting one or more of your original search criteria is sufficient to improve search results. For example, if you are having difficulty finding published information on interventions in a particular

state to prevent teenage girls from smoking, you could broaden your search to look for any studies conducted in any jurisdiction in the United States. There may have been studies done in specific cities or in other states that would provide interesting and useful information. You could also consider broadening your search to include studies that looked at smoking prevention programs for both girls and boys.

IV. Appraise

As information is being gathered, it is essential that you appraise it for accuracy and reliability. It is important to appraise both the limitations and biases that are inherent in any single source of information, as well as to evaluate the body of information on a topic as a whole. A number of biases can affect what research gets published. "Publication bias" involves the increased likelihood that research which shows a positive result will be published, compared to research that shows no result (Easterbrook, 1991). This can lead to an unbalanced view that, for example, a particular intervention is worthwhile, when perhaps many other unpublished studies had found no impact from the intervention.

It has also been suggested that there is a bias favoring publication of studies conducted in wealthy countries over those conducted in less-developed parts of the world (Yousefi-Nooraie, 2006). A number of specialized databases have been developed in an attempt to improve access to international studies. For example, several online databases have been developed to index the health research literature from areas of the world which may be otherwise under-represented. These include the *African Index Medicus*, the *Index Medicus for the Eastern Mediterranean Region*, the *Latin American and Caribbean Health Sciences database (LILACS)*, and the *Index Medicus for [the] South-East Asia Region (IMSEAR)*. An increasing number of these articles are available at no cost online, but if not, in most cases a library in the United States will be able to obtain copies of articles via the existing widespread interlibrary loan network. Keep in mind that some of the studies may have been published in languages other than English, although abstracts are often available in translation. If that is the case the motivated reader without the necessary language skills will have to have the article translated.

Conflict of interest also raises serious questions of potential bias. For example, studies have shown that pharmaceutical industry sponsored research is less likely to be published and is more likely to report favorable results when it is published. (Montaner, 2001) Concerns have also been raised about the control which company sponsors have over researchers' ability to publish their results, and there have been numerous reports of research results being suppressed by the research sponsor (Bodenheimer, 2000).

A movement toward clinical trial registries is an attempt to ensure that particular types of medical research do not "disappear" due to lack of publication. In 2007, the World Health Organization announced development of the International Clinical Trial Registry Platform (ICTRP), stating that "the registration of all interventional trials is a scientific, ethical and moral responsibility". (World Health Organization, 2007) While trial registration is voluntary, it is widely supported in the research community and many major journals now require prior registration in order to consider publication of research results from a clinical trial (Laine, 2007)

Publication trends and the high cost of information, especially scientific journal subscriptions, can further limit access to published information. The emerging "open access" movement is attempting to address these concerns by developing online publishing models which anyone can access without a subscription. While the economics of open access publishing have been questioned (Anderson, 2004), proponents argue that open access publishing "signifies the democratization of knowledge and supports a socially responsible way to distribute knowledge" by increasing access to information regardless of a person's ability to pay (Yiotis, 2005, p. 160). Part of the open access movement has been a push to make available all publications arising out of National Institutes of Health (NIH) funded studies, since U.S. taxpayers have already subsidized this research. The NIH Public Access Policy implemented in 2005 "requests that investigators funded by the National Institutes of Health (NIH) submit an electronic version of their final, peer-reviewed manuscripts upon acceptance for publication" so they can be put up on the National Library of Medicine's public website Pubmed Central. (National Institutes of Health, 2005) While this is a voluntary policy, legislation is pending in the U.S. Congress that would require public availability within 12 months of publication (Alliance for Taxpayer Access, 2007).

Social, political, or ideological biases can also affect what is studied, how much is published, and the nature of what is published about a particular topic. Research using stem cells derived from human embryos is currently very controversial, with the U.S. government banning use of federal funds for such research and thus limiting the amount of research done in this area. Such ethical controversies are not new. Information available about abortion is affected by the ongoing controversy surrounding the various procedures and various countries' laws relating to abortion which have changed over the decades. The Diagnostic and Statistical Manual of Mental Disorders, a listing of psychiatric disorders, classified homosexuality as a "sociopathic personality disturbance" in 1952, but eventually removed it from the manual altogether in 1973 as attitudes about homosexuality changed (Bynum, 2002).

Screening processes are also in place for deciding which submitted articles will be published in a particular journal. The most common method of screening scholarly literature prior to publication is peer review. Peer review involves having one or more experts evaluate an article prior to its acceptance for publication. Often articles are "blinded" so that the peer reviewer cannot, at least in theory, identify who the author is. In this way it is hoped that only well-done research with reliable conclusions will be published. However, this system has come under significant criticism over the years as being inconsistent, subject to bias, unduly delaying publication, unable to detect fraud, and prone to stifling innovation (Benos, 2007). Peer review can be helpful in screening for quality, but does not take the place of the reader's responsibility to critically appraise all information gathered.

Special care must be taken when using health-related information found on websites that have not undergone the peer-review process of scholarly journal articles or the editorial process of scholarly books. Numerous studies have been done evaluating the quality of health information on the Internet for specific topics. Summers and Logsdon looked specifically at postpartum depression information on the Internet and found it woefully unreliable. None of the top 10 websites they retrieved on each of eleven different web search engines had completely correct information, and some sites contained potentially harmful information (Summers, 2005). Similar quality deficiencies have been identified by studies that looked at websites on melanoma

(Bichakjian), asthma (Croft), emergency contraception (Latthe), scoliosis (Mathur), and osteoporosis (Perez-Lopez). Clearly a researcher must take great care in relying on information gathered from websites. A conscientious researcher should seek out more consistently reliable peer-reviewed sources, rather than relying heavily on websites. When websites provide unique information, every effort should be made to carefully review it with a critical eye, and if possible to verify the information with an independent source. Table 2 provides a list of criteria to consider when appraising information from any source.

A number of specialized search engines and quality criteria standards have been developed in an attempt to overcome concerns about the relevance and quality of health information retrieved by using general Internet search engines. HONCode is a international, non-profit, non-governmental organization created in 1995 with the stated goal of providing an ethical code for health information on the Internet (Health On the Net Foundation). HONCode provides a certification process for websites that agree to abide by its ethical code, which addresses privacy as well as quality and trustworthiness of websites. The HONCode website (<http://www.hon.ch/>) also provides various search tools for finding health information from websites which abide by the HONCode standards. Other web gateways and search engines which provide some selection and pre-screening of websites for health information include MedlinePlus (<http://medlineplus.gov/>), healthfinder.gov, and Intute (<http://www.intute.ac.uk/>). While such sites offer some assurance of relevance and quality, health research is constantly advancing and websites also change over time. The individual researcher still needs to be the final evaluator of any information retrieved from the Internet.

V. Apply

Once information has been gathered and evaluated, it is time to apply it. The way this is done will vary with the researcher's purpose. For a scholarly article, this may involve synthesizing the information in the form of a literature review. The literature review may be an end in itself, or a means of putting original research into context.

In the area of health care practice – including medicine, nursing, and public health -- the “evidence based” paradigm has been widely adopted as a method of applying research findings to real-life situations. “Evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research,” including consideration of “individual patients’ predicaments, rights, and preferences in making clinical decisions about their care” (Sackett, 1996, p. 71). An evidence based approach holds promise for improving not just individual patient outcomes, but also for improving health care delivery systems.

However, while the paradigm of evidence based health care (EBHC) is widely embraced, it is imperfectly practiced. John Wennberg, a researcher who studies geographic variations in U.S. health care quality, has argued that improved science, including “the capacity to distinguish what really works,” is needed to improve quality of care nationally (2004, p. 4). Reasons cited for the failure of EBHC to live up to its promise include providers’ failure to align their practice with the existing scientific evidence (Timmermans, 2005), as well as lack of consistency in producing, gathering and applying existing evidence and a lack of any good evidence in many areas (Steinberg, 2005). Globally, politics and poverty can stand as intractable barriers to implementing even well-established health care treatments and public health improvements (Paluzzi, 2005). Even in developed countries, it has been estimated that it takes an average of seventeen years for research findings to be routinely incorporated into clinical practice (Balas, 2000).

As a result of these difficulties many health care questions and problems remain unstudied or unaddressed. It is therefore possible that a question posed will turn out to be impossible to answer from the existing available research literature even after a thorough search. If this occurs, one alternative is to re-frame the question to something that is more readily answered but still useful. You can also choose to accept information that is not perfectly applicable but that is somewhat relevant and note the limitations of the available research. In a practice setting it is unfortunately very common to have to act based on less than conclusive evidence.

Conclusion

The “ask, acquire, appraise, apply” approach provides a useful framework for researching health studies questions in the existing literature. As has been discussed, however, this process is not always simple and straightforward. Researchers should be aware of the limitations of the publication and peer-review process and recognize the many potential biases in the published literature. Researchers need to be especially careful in evaluating health information found on the Internet, a great deal of which has been found to be inaccurate. It is also important to be aware of the barriers which can limit production of research and dissemination of research results. Consulting with a librarian and experts in the field can be helpful for identifying reliable sources of information and effective search strategies. The best information research approach is one which involves a search of multiple sources and engages the reader’s critical thinking skills in each step of the process.

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Table 1: Examples of major information sources for health studies
NOTE: good research requires use of multiple databases and sources; this is a highly selected list for illustrative purposes only.

Type of information	Example of Database/Source
scholarly articles; scientific information for clinical research & practice	PubMed http://pubmed.gov/ Web of Science (subscription database) African Index Medicus http://indexmedicus.afro.who.int/
population based information to support research in sociology, anthropology or public health	POPLINE ® http://db.jhuccp.org/ics-wpd/popweb/
information for healthcare consumers	MedlinePlus http://medlineplus.gov/ healthfinder.gov http://healthfinder.gov/
information to support healthcare policy decision making	CDC Guide to Community Preventive Services http://www.thecommunityguide.org/ Center for Health Improvement's Health Policy Guide http://www.healthpolicyguide.org/ Dartmouth Atlas of Health Care http://www.dartmouthatlas.org/
global health issues & statistics	World Health Organization http://www.who.int/ Doctors Without Borders/Médecins Sans Frontières http://www.doctorswithoutborders.org/
health statistics	(U.S.) National Center for Health Statistics http://www.cdc.gov/nchs/ Pennsylvania Bureau of Health Statistics & Research http://www.dsf.health.state.pa.us/health/cwp/view.asp?a=175&Q=228721
Data sets	CDC Wide-ranging OnLine Data for Epidemiologic Research (WONDER) http://wonder.cdc.gov/ Centers for Medicare & Medicaid Services http://www.cms.hhs.gov/home/rsds.asp

	Inter-university Consortium for Political and Social Research (ICPSR) (membership/fee based service) http://www.icpsr.umich.edu/
specialized health web search engines	HONCode Hunt http://www.hon.ch/HONcode/Hunt/ Intute http://www.intute.ac.uk/

Table 2: Criteria for Appraising Information

Relevance	Is the information appropriate to your research purpose? For example, does it apply to the population you are researching?
Publication/Publisher/Organization	Is the publisher, publication or organization publishing the information respectable? What is the peer-review procedure followed (if any)?
Author	Is the author expert in the field about which s/he is writing? If no individual author is given (as with some websites) is the organization making the information available reliable?
Overall quality of the writing	Is the piece well written (grammar, spelling, etc.)?
Date	Is the information current?
Accuracy/Plausibility	Is the information credible? Are the author's assertions reasonable and well-supported? Are the presented facts consistent with what you know to be true, or with other research you have done?
Evidence of research	Are references cited? Are the references current? Do they seem appropriately selected to support the piece?
Research methodology/sample size	For research articles, is the methodology appropriate to what is being studied? Are there any weaknesses in the methodology? Is the study population large enough to draw conclusions?
Biases, e.g., <ul style="list-style-type: none"> • Conflict of interest • Ideological bias • Publication bias 	What biases are present? Note: evidence of bias does not mean a piece must be rejected, but indicates a need to find other sources to provide balance.