

PATHWAYS

# Understanding Ethics and Privacy in Health Information and Services



**Health Happens  
In Libraries**

This project is made possible by the  
Institute of Museum and Library Services.



# Understanding Ethics and Privacy in Health Information and Services

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## Overview

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### *What are ethics?*

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**Ethics** are value-charged standards that staff working in a specific profession, industry or type of business agree to follow.

### *Why do ethics matter to the community?*

A code of ethics guides the behavior of those who work in the public library, so that both staff and the community know what library staff should and must not do in order to provide appropriate library services. Unlike morals, the prescription for the “right way” to interact is not personal, but professional.

### *Why do ethics matter to the library?*

Codes of ethics are not secret. In fact, in your health information work, you may need to research ethical codes that apply to health professions such as physicians, other clinicians or drug researchers. Library staff who design and deliver information services can fine tune both ethical and knowledge skill-sets to provide community members with appropriate health, healthcare access and health maintenance information.

### *What areas of guidance are available in this pathway?*

Along this pathway, you can explore three ethical areas that inform your library work regarding health information services for your community, as well as related resources and actions.

These areas include:

- ♦ How to Provide Ethical Guidance When You Aren't a Health Expert
- ♦ Ethical Communication Practices When You and the Person with a Health Question Speak Different Languages
- ♦ Ethical Collection Maintenance for Health Information Consumers

# How to Provide Ethical Guidance When You Aren't a Health Expert

## Review this section to...

- ♥ Understand the role of professional ethics as a guide in your library health information work
- ♥ Identify ethical considerations to make when providing health and wellness information to your community

## Public Library Scenario



Kim was worried. At the county staff meeting that morning, several other department heads had asked a lot of questions about how the library was handling health information questions.

“You’re there alone, Kim, with just Tom helping with shelving a couple mornings a week. I’m sure neither one of you has any medical training. Yet you’re telling us that members of the community are using the library to find out about Obamacare and how to apply. And then you said that you’d like to offer the laptop lab to folks looking for healthcare information online. I don’t think the library belongs in this political business. Besides, you might give them the wrong information,” the County Clerk said.

“I’m pretty sure Kim can handle the laptop lab,” said the Assistant County Manager. “What concerns me is whether kids will be asking for birth control information at the library now. Do you think we should be offering that kind of stuff to middle schoolers, Kim?”

Kim knew that these questions weren’t intended to be rebukes, but they did call attention to some of the very worries that Kim and Tom had discussed over coffee last week about the library’s role in providing health information and services.

### Key Concept

*Key ethical standards to keep in mind include distinguishing between our personal beliefs and responsibility for providing requested information, along with a commitment to enhancing our knowledge and skill as information providers.*

# Resources and Actions to Help You Maintain Ethical Standards

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Each library should adopt a code of ethics that can be presented to the public and that helps to guide internal actions and decisions. This may require discussion with and approval from the library board or trustees. The American Library Association (ALA), has created a Code of Ethics that many libraries and library staff adhere to; it would be a good resource to review and potentially adopt. The [seventh principle of the ALA Code of Ethics](#) states:

We distinguish between our personal convictions and professional duties and do not allow our personal beliefs to interfere with fair representation of the aims of our institutions or the provision of access to their information resources.

The [final principle of the Code](#) notes:

We strive for excellence in the profession by maintaining and enhancing our own knowledge and skills, by encouraging the professional development of co-workers, and by fostering the aspirations of potential members of the profession.

The Reference and User Services Association (RUSA) [Guidelines for Behavioral Performance](#), governing information and referral services, identifies principles related to guiding community members to appropriate resources. The basic information specialist ethical principles have also been applied to form the [Medical Library Association's \(MLA\) Code of Ethics](#), for health sciences librarianship. When your public library works with health information and with community members who want and/or need to find health information, the MLA Code of Ethics can be used as the framework for your library staff as well.

RUSA [Guidelines for Medical, Legal, and Business Responses](#), Sections 1.0.1–1.0.8, indicate expectations for library staff who are fulfilling the duties of information services for their community. Section 1.0.5 states:

Information services staff members are responsible for providing complete and accurate responses to users' questions when possible and for guiding library users to the most appropriate resources for their information needs.

[Finding Health and Wellness @ the Library](#) provides immediate access to ways you can update your awareness of health resources in print, online and audiovisual formats. It also lists places to find no-cost and low-cost training for public library staff who need to enhance their awareness of the competencies underlying ethically sound health information guidance to their communities. This toolkit lists eight competencies for library staff who work with health information consumers.

From these, we can outline the fundamental steps involved in responding to health and wellness-related reference questions:

♦ **Provide a welcoming, safe environment that shows respect for privacy.**

You can do this by identifying a private area where confidential topics can be more comfortably discussed. If there is not privacy at the reference desk, take the person to the book stacks or another quiet area. Lower your voice to maintain privacy. During a reference interview, someone with a health question may be reluctant to specify information because of the nature of the health condition, so explain your reasons for wanting to know. Consider saying, “It will help me to find the information you need if you can tell me more about what you want to know.” Emphasize that you will respect his or her privacy.

♦ **Be aware of the person asking the question without making assumptions you do not know to be true in this situation.**

Parents, other family members or friends may be asking for information for a loved one. A homework assignment may be for a science course or a debate class. Determine the age and gender of the person affected by a health concern in question. A medical condition may affect a child differently than an adult, and treatments can vary depending on age and gender.

♦ **Take into consideration, without judging, the person’s emotional state.**

The community member with whom you are speaking may be upset and not clear about the information he needs. Be empathetic, patient and nonjudgmental.

♦ **Be aware of your own body language.**

Avoid agreeing or disagreeing with what the other person expresses. Use active listening phrases like “I understand” or “Tell me about that, please,” instead of “I know” or “That always seems to be the way it goes.” Do not offer your own experiences or hearsay about similar medical conditions. Be mindful of where your personal beliefs might intrude on your delivery of the information requested to guard against behaving less than ethically.

♦ **Verify medical terminology in a medical dictionary or encyclopedia.**

The person you are helping might not know the correct medical terminology to describe her health condition. Always verify unfamiliar terms in a medical dictionary. A free and up to date one is available in [MedlinePlus](#). Be cautious with medication names: some drugs have similar names but very different uses.

♦ **Be aware of the limitations of medical information.**

Medical information becomes quickly outdated, medical experts do not always agree about how to diagnose and treat a specific disease, and most medical information is written in technical terms. Know when you have reached the limits of your collection, and express these limitations to the community member. Be prepared to send users to other valid sources of information.

♦ **Provide the most complete information to answer the information request.**

This can be challenging when responding to some health questions. A person may have a question about the prognosis of a specific disease that you learn is usually fatal. What should you do? You should not withhold information because this can be considered a form of censorship. Some people who want information about a serious disease may already suspect the prognosis. Emphasize that every situation is different, and that the individual should discuss the issue with his or her healthcare provider instead of interpreting the information on his or her own. If the topic is one about which you hold personal beliefs, you may not allow that to interfere with your presentation of complete service, nor may you present your own viewpoint.

♥ **Do not interpret medical information.**

Do not attempt to provide a diagnosis or recommend a therapy or intervention. Emphasize to the community member that you are an information professional, not a health professional. When discussing consumer health issues in person, on the telephone or via e-mail, state the limitations of your role as an information professional and the limitations of your collection. Direct the person to consult with his or her healthcare provider for interpretation or explanation of the information. Add a disclaimer statement to library publications, including signage.

♥ **Provide referrals.**

Note that a referral is different from a recommendation. Do not recommend a particular care provider, insurance carrier or treatment plan.

[MedlinePlus Directories](#) is the authoritative resource for finding local, state, or national care provider referrals. Building and maintaining community partnerships with healthcare providers also provides you with an immediate support system in your information work. These potential partners include staff at:

- ♥ Hospital libraries
- ♥ Public health agencies
- ♥ Local clinics that serve the needs of women, infants, children, those in substance abuse recovery and mental health consumers

[Children and youth have the same access rights to information](#) as do adults in the community. Information services on sensitive issues, such as birth control, cannot be provided to adults and denied to youth. Become familiar with ALA's [Library Bill of Rights](#) and make sure that your library board or supervising agency knows about its ethical ramifications on library staff and community services.

The Library Bill of Rights interpretation statement [Labeling and Rating Systems](#) clearly indicates that it is not ethical to determine for the library user which resources have “better” ways of thinking about a topic, including a health topic, than others. That doesn't mean that some resources have greater or less authority. In matters of consumer health information, authority is the key quality to identify in library sources, not whether the information is morally right or wrong. You can help users determine authority of a source by noting the subject-specific background of the author as well as the intent or sponsorship of the author's publication, not whether you agree or disagree with the author's politics or the publication's presentation.

# Identify Solutions

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Reflecting on Kim's situation in the public library scenario, take a few moments to consider and document recommendations on the following:

*What is a concise and clear explanation that Kim could provide to concerned department heads about the library's role in providing health information and services?*

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*How does the provision of health information and services align with your library's code of ethics, stated values or service expectations?*

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# Ethical Communication Practices When You and the Person with a Health Question Speak Different Languages

## *Review this section to...*

- ◆ *Recognize community needs for the application of ethical information standards in planning for and responding to diverse communication capacities*

## Public Library Scenario



Shawn greeted the woman and grade school aged boy with, “Good evening. Can I help you?” The woman, who looked perhaps worried or nervous or even both, returned the “Good evening” and Shawn noted her heavily Russian-accented English. The boy gazed over Shawn’s shoulder and shifted from foot to foot, quiet and maybe bored or just wishing he were elsewhere.

“I am legally here. My husband is not here. Can we get insurance anyway?”

Shawn knew a further reference interview was needed in order to clarify the actual question the woman wanted addressed. And Shawn didn’t speak or understand Russian and couldn’t think of anyone else on staff and in the building who might.

“Do you feel comfortable discussing this in English?” Shawn asked tentatively. “It might be complicated.”

“No,” the woman responded immediately. “That’s why I brought my son. He speaks Russian and English.”

### *Key Concept*

*Confidentiality and equitable access for all are the key ethical standards here.*



# Resources and Actions to Help You Maintain Ethical Standards

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The [first principle of the ALA Code of Ethics](#) is:

We provide the highest level of service to all library users through appropriate and usefully organized resources; equitable service policies; equitable access; and accurate, unbiased, and courteous responses to all requests.

The [third principle of the ALA Code of Ethics](#) is:

We protect each library user's right to privacy and confidentiality with respect to information sought or received and resources consulted, borrowed, acquired or transmitted.

It is important not to refer the translation work to a child accompanying the person with the health question or ask another member of the public to serve as an unofficial translator. The person with the health question must have her or his confidentiality honored and to do either of these things would break confidentiality (and, in the case of the child, potentially expose that child to information she or he cannot handle developmentally). To rely on any but authorized interpreters also interferes with the ethical principle of equitable treatment because you would not take either of these actions with a community member with whom you share a fluent language; instead, you would honor their inquiry with the level of confidentiality and professionalism you bring to other inquiries.

[Language Line](#) is the professional interpretative service used by the federal, state and many local governments to bridge shared language gaps between clients and service providers. This service provides professional (trained and licensed) interpreters in more than 150 languages and is used by the federal and many state governments to facilitate healthcare insurance market access. Language Line requires only a telephone, the access code that a subscription to the service makes available for use by any staff member the subscriber authorizes, and—depending on how uncommon a language might be—some patience while an appropriate translator can be connected.

To prepare for situations where interpretation might be necessary:

- Be sure you know whether your library, or your library's governing district, subscribes to [Language Line](#). A local hospital or school district may be the subscriber in your area. If that's the case, here is a great opportunity for you to build a partnership.
- If no local subscription can be located, remember that your state and the federal government both make it accessible for assistance with healthcare access needs. Read the [FAQs](#) about how Language Line works.
- If your library supports staff use of a second language for work purposes, be sure you know on which staff member you can call for translation assistance. Other local agencies may also have staff members able to provide translation support through partnership. All translators should be informed about the ethical ramifications of information work, including confidentiality and the bar on giving personal opinions about health matters.

# Identify Solutions

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Reflecting on Shawn's situation in the public library scenario, take a few moments to consider and document recommendations on the following:

*What translation services are currently available to patrons in your community, either through the library or other local partners?*

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*How might you raise awareness of translation services in your community, particularly to patrons who may be hesitant to seek assistance due to perceived language barriers?*

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*What space/areas in your library can you use to have more private conversations if the topic is potentially sensitive?*

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# Ethical Collection Maintenance for Health Information Consumers

*Review this section to...*

♥ *Build appropriate health information access points into library collections*

## Public Library Scenario



Leslie has been working on weeding the library's cookbook section. Books that had been returned obviously damaged had already been pulled aside, so now it was a matter of considering what else might be a candidate for retirement.

Leslie noticed that the cookbook section included a number of books addressing cooking for specific health conditions, like diabetes, heart disease and even ADHD. A quick look inside some of these showed Leslie two facts: first, these books were definitely enjoying attention by current borrowers, and second, their publication dates were all more than two decades back.

Maybe these books had newer editions to replace these? Leslie checked and discovered that, no, for all the ones he had just brought back to the computer from the shelf, there had been no newer publication.

And yet, the community certainly was showing an interest in using these so did it really matter? After all, they were cookbooks, not medical guides.

### *Key Concept*

*The three key ethical principles of confidentiality, equitable treatment and provision of service without regard to your own personal beliefs should inform your library's collections that are intended for health information seekers.*

# Resources and Actions to Help You Maintain Ethical Standards

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- ♦ Ensure that health information titles presented to the community are up to date.
  - ♦ Weed outdated materials, especially checking such collection areas as diet and home care for chronic conditions.
- ♦ Verify that health information titles are presented in the language(s) read by the community, including established sectors of the community who connect primarily with languages other than English and those for whom plain language (rather than technical) is essential for accessing relevant information.
  - ♦ Make use of [health information in multiple languages from MedlinePlus](#) and other authoritative Web resources to provide text-based health information otherwise unrepresented in the materials collection, or presented in only limited language access modes.
- ♦ Investigate and apply your knowledge of local health priorities to collection development.
  - ♦ Consult with public health agencies and schools about community prevalence of chronic conditions such as asthma and diabetes.
  - ♦ Follow your library's public posting policies to assist community health partners in providing notice to community members about school vaccine, flu and other seasonal clinics.

# Identify Solutions

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Reflecting on Leslie's situation in the public library scenario, take a few moments to consider and document recommendations on the following:

*What tactics does your library use to gather information from the community on topics or resources that are relevant to them?*

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*What can you do to ensure the inclusion of health information or service topics in that process?*

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*What health and wellness resources can supplement the library's print collection and how could you publicize these?*

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